

**The psychosocial experiences of partners of
people with aphasia: the evolution of an
idiographic, qualitative methodology**

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ABSTRACT

This thesis is concerned with understanding the psychosocial effects of aphasia for partners, and with the outcomes and processes of group programmes of support and conversation training. It comprises three studies, each of which builds upon the other in method and depth.

Study One utilised the quantitative, idiographic Personal Questionnaire Rapid Scaling Technique (Mulhall, 1978) to examine the psychosocial issues of 12 partners of people with aphasia (PWA) before and throughout the programmes. Individual statistical analysis suggested that the scores of four partners showed significant positive change as a result of the support programme, and two changed as a result of the conversation training programme. Results were achieved by considerable data reduction, so changes in individual issues could not be determined. Study Two therefore shifted from the quantitative, researcher's perspective to a method able to capture more fully insider perspectives. The Framework Method (Ritchie and Spencer, 1994) was used to analyse semi-structured interview data from the programme participants. This highlighted, within broad themes, varied and interacting factors that influenced participation and psychosocial change: programme content and organisation, individual circumstances, group and personal processes. The predominant focus of Study Two's findings was the process of intervention, leaving the essential question of how partners *really* experience psychosocial life with PWA unanswered. By taking a further qualitative shift, Study Three answers that question for one woman. An interpretative phenomenological analysis (Smith, 1996) of her in-depth interview suggests her experience was a complicated process of accommodation linked to life pre-stroke and post-stroke. This process featured complex phases labelled as 'rescue mission and hope', 'endurance, loss and hopelessness' and, finally, 'regeneration'. These phases were linked to her changing perception of her relationship with her husband, her role and her self-image.

The thesis concludes with a discussion of methodology, theoretical findings and avenues for further research.

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GLOSSARY OF ABBREVIATIONS

ADL	Activities of daily living
CA	Conversation analysis
CAPPA	Conversation Analysis Profile for People with Aphasia
CAT	Comprehensive Aphasia Test
CETI	Communicative Effectiveness Index
CP	Conversation Programme
CWC	Coping With Communicating
FM	Framework Method
GHQ	General Health Questionnaire
HADS	Hospital Anxiety and Depression Scale
IPA	Interpretative Phenomenological Analysis
OCSF	Oxford Community Stroke Project
PAM	Professions Allied to Medicine
POSI	Perception of Stroke Issues
PQRST	Personal Questionnaire Rapid Scaling Technique
PWA	Person/people with aphasia
RCT	Randomised Control Trial
S1	Study One
S2	Study Two
S3	Study Three
SLT	Speech and language therapy/therapist
SP	Support Programme
TIA	Transient ischaemic attack
TO1	Therapy Order 1
TO2	Therapy Order 2

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CHAPTER 1

INTRODUCTION TO THE THESIS

'It's a total change in my life'

These few words capture the effect that stroke and aphasia has had on the psychosocial life of their speaker. They are not the words of a stroke survivor, whose life might be expected to change dramatically as a result of communication and physical difficulties post-stroke, but of his wife. Her quote captures the essence of this thesis, the overall aim of which is to provide greater understanding of psychosocial change for partners resulting from a relative's stroke and aphasia. More specifically, the thesis attempts to understand the *nature* of that psychosocial change, partners' experiences and the effects of two types of group intervention programmes.

The quote above can also be used to illustrate the evolution of my research journey. The work for the thesis developed my clinical practice and created a shift in my ontological and epistemological perspectives. It changed my views on measures and methods for understanding individuals' experiences and perspectives and evaluating therapy outcome and process. This journey, and the evolution of the structure and content of the thesis, is now summarised.

The thesis originated in and advances a Tavistock Trust-funded research project entitled 'Coping With Communicating' (CWC), which took place in the Department of Human Communication Science at University College London between 1996 and 1999. As the research fellow and speech and language therapist on the project, I was responsible for its day-to-day running and co-ordination. I participated in the collation and design of a range of assessment measures. I was responsible for recruiting and assessing participants, and planning, facilitating and evaluating domiciliary and group programmes of support and conversation training for partners of people with aphasia (PWA). I and the CWC team evaluated the effect that these programmes had on the impairments, disabilities and handicaps¹ of the PWA during the project, but the effect of the group programmes on the partners' psychosocial state became the task of this thesis.

To date, partners of PWA have received minimal research and clinical attention. At the inception of CWC project there were notably few published studies available about speech and language therapist-led intervention for partners. What existed suggested that the effects of interventions on partners' psychosocial state could be assessed objectively

¹ as defined by the World Health Organisation (WHO) (1980)

and statistically using published measures. We therefore chose the Personal Questionnaire Rapid Scaling Technique (PQRST) (Mulhall, 1978) to measure the psychosocial effects of our groups. This was recommended in some pertinent literature for its ability to provide idiographic (ie derived from and unique to the individual) information that could then be quantified and analysed statistically to give objective results. Also, it appeared to offer a format which was 'manageable' when transferred to a clinical rather than a research setting, a factor the CWC team felt was vital in ensuring our research outcome measure was as clinically applicable as possible. The first study of this thesis comprises the findings and critical exploration of that assessment.

Once the CWC assessment and programme sessions were underway, my perceptions of myself as objective researcher and of participants as 'research subjects' were challenged, as was my notion of the desirability and attainability of apparently objective evidence. Through the processes of assessing participants, listening to their stories of their lives being significantly disrupted by their relatives' communication and physical impairments, facilitating sessions and observing their experiences and interactions in the groups, I developed close relationships with them. I wanted personally to do justice to their experiences. Perhaps more crucially from a research and clinical agenda, I recognised the importance of documenting the partners' own very different psychosocial experiences and perceptions of the effects of their participation and interactions in the groups. It became obvious that any reported outcome that did not consider these would be not only incomplete, but potentially erroneous, and definitely of limited value in shaping the development of theoretically- and evidence-based group-work practice for partners. However, they were impossible to capture using the measure originally chosen for the CWC project, or any of the objective, quantitative assessments known to me or the team. A shift from researcher-centred, quantitative assessment to a qualitative paradigm capable of more fully accessing and revealing insider perspectives was required. At the end of their involvement in the project, therefore, participants took part in semi-structured interviews with a fellow group member who had also taken an academic interest in the research, and had experience of research interviewing. This innovative approach to service evaluation thus enabled the partners to define their own experiences in their own words, and to tell their stories of the effects of the groups in an open, honest and safe environment. Study Two of the thesis presents the findings from those interviews. It also appraises the 'Framework Method' (FM) of data analysis (Ritchie and Spencer, 1994), with which the data in Study Two was analysed. Although

FM was designed for use in applied social policy research, it had been shown to effectively uncover the experiences of people with aphasia (Parr, Byng, Gilpin and Ireland, 1997). It has also been used in an evaluation study (Spencer and Whelan, 1988), though when the work for Study Two took place it had yet to be utilised or evaluated in a study of this nature.

The third and final study of the thesis both derived and is a departure from the work carried out for the CWC Project and Studies One and Two. Its aim is to ‘fill in the gaps’ from those studies, which provided clues about psychosocial change for partners living with a stroke survivor with aphasia, but an incomplete understanding of the nature and extent of that change. Study Three therefore provides an in-depth exploration of the experience of one partner, the woman who provided the quote at the beginning of this introduction. ‘Saskia’ was not involved in the CWC Project, but took part in an interview with me for the sole purpose of this thesis. The research aim and question of Study Three and the method used to explore them needed to enable the in-depth investigation of issues that had not been fully addressed so far in this thesis, for methodological reasons, or in other research to date. They also needed to be able to capture complex and subjective matter from a holistic perspective. The study therefore adopted a further shift towards an idiographic, inductive, interpretative qualitative research method, and the interview was analysed using the method of Interpretative Phenomenological Analysis (IPA), developed by Smith and his colleagues (Smith 1995; Smith, Flowers and Osborn, 1997; Smith Jarman and Osborn, 1999). This method has now been widely used in the field of health psychology and has been valuable in uncovering individual perspectives about a range of personal experiences (Jarman, Smith and Walsh, 1997; Smith et al, 1997; Osborn and Smith, 1998; Smith et al, 1999). However, its use in the third study of this thesis is its first known utilisation within aphasiology or about the long-term psychosocial effects of stroke and aphasia for partners. Study Three explores the findings of the interview analysis and provides a critical exploration of the research method.

1.1 The structure of the thesis

This thesis consists of three distinct but related studies, all of which have at their heart the psychosocial experiences of partners of PWA. Because the aims, research questions

and methodology of each study are distinct, though related, they are not documented centrally, but with each study as it is presented.

The structure of the thesis is as follows:

Chapter 2: Literature review

This literature review provides the context and rationale for the study of the psychosocial effects of aphasia for partners and for the provision of speech and language therapy-facilitated services for partners. Chapter 2.1 provides an overview of stroke and its effects on the PWA, and outlines current pertinent definitions of aphasia. Chapter 2.2 defines 'psychosocial' and 'partners' as they are conceptualised in the literature and for this thesis. It places psychosocial research in aphasiology within a historical context and discusses the importance of partner research. In recognition of the systemic links between the PWA and his primary partner, the substantive findings from the literature about a range of psychosocial effects for the PWA are reviewed in Chapter 2.3. Those related to partners themselves are described in Chapter 2.4, along with a review of research about factors that influence coping with caring and resultant psychosocial changes. In the absence of a significant body of literature pertaining specifically to partners of PWA, relevant literature on partners of people with stroke in general or with other similar chronic illnesses are also reviewed where appropriate. Finally, Chapter 2.5 reviews the small body of literature, which has evaluated psychosocially-orientated SLT services for partners. This is provided within an analysis of the different perspectives from which partners have been perceived in this type of work, ie as resources for the PWA, as superseded, as co-workers or as co-clients. Two papers which particularly influenced the work for Studies One and Two of this thesis are reviewed in depth.

Chapter 3: Study One

Study One evaluates the effects of a group support programme and a group conversation training programme on the psychosocial state of partners of PWA, as judged using the PQRST (Mulhall, 1978). It also critically evaluates the research and clinical utility of the assessment measure.

Chapter 4: Insider perspectives and the qualitative paradigm

This chapter explores the evolution of the thesis in terms of its shift towards accessing insider perspectives and the adoption of a qualitative paradigm. It thereby sets the scene and provides theoretical context for Studies Two and Three. Literature reviewed in Chapter 4 was not included earlier with that related to the whole thesis, as the issues it explores were raised as a result of problems with the methodology and findings of Study One. Chapter 4.1 briefly explains the shortcomings of researcher perspectives and the quantitative paradigm. Chapter 4.2 introduces the role of the qualitative methodology in accessing and understanding insider perspectives, and in programme and process evaluation. It also introduces and provides a rationale for the use of Framework Method (Ritchie and Spencer, 1994) of analysis utilised in Study Two. Chapter 4.3 describes the strengths, limitations and challenges of qualitative methodology and highlights methods for ensuring trustworthiness. Finally, Chapter 4.4 summarises some ethical issues particular to this paradigm.

Chapter 5: Study Two

Study Two evaluates the support and conversation training programmes featured in Study One from the perspectives of the participants. It attempts to uncover and report the factors that influenced their participation in the programmes and resultant psychosocial change. It critically evaluates the research and clinical utility of the Framework Method of qualitative data analysis.

Chapter 6: Study Three

Study Three provides the rationale for and describes the use of Interpretative Phenomenological Analysis (IPA) (Smith, 1995) in accessing and understanding the psychosocial experiences of a spouse of a PWA. This is an in-depth individual case study, which aims to address the methodological limitations of the previous two studies.

Chapter 7: Thesis conclusions

The final chapter brings together and discusses the key findings of the three studies and provides overall conclusions and recommendations about methods, theory, clinical practice and future research.

CHAPTER 2

LITERATURE REVIEW

Introduction

This chapter reviews literature that provides the context and rationale for the study of the psychosocial effects of aphasia for partners and for the provision of speech and language therapy-facilitated services for partners.

2.1 Stroke, aphasia and their effect on the PWA

Although it will be shown that partners of people with aphasia are worthy of study in their own right, their needs cannot be considered fully without placing them within a context of the PWA. Chapter 2.1 begins to provide this context. It supplies a definition of stroke and some statistical information. It briefly describes some of the common impairments resulting from stroke and provides an overview of some current views on definitions of aphasia.

2.1.1 Definition of stroke

Stroke has been defined by the World Health Organisation as ‘a syndrome of rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no apparent cause other than of vascular origin’ (Hatano, 1976). Transient ischaemic attacks (TIA) are distinguished from strokes solely by the duration of their symptoms: TIAs last for less than 24 hours. A review of the causes and risk factors of stroke can be found in Ebrahim (1990) and Wade, Langton-Hewer, Skilbeck and David (1985).

2.1.2 Statistics

Every year over 100,000 people in England and Wales have a first stroke. Stroke accounts for over 8% and 13% of all deaths in men and women respectively in England (Stroke Association, 2002), making it the third most common cause of death after heart disease and cancer. 88% of deaths are in people over 65 (Wolfe, 1996). The Oxfordshire Community Stroke Project (OCSP) reported overall case fatality of 19% at four weeks post-stroke, 31% at one year and about 45% at five years (Bamford, Sandercock, Dennis, Burn and Warlow, 1990; Warlow, Dennis, van Gijn, Hankey, Sandercock and Bamford, 1996). Mortality rates from stroke have declined, however, and more people now survive for longer: in England and Wales the rate of decline between 1970 and

1985 was 3% per annum (Warlow et al, 1996). See Wolfe (1996) for rates in other countries, and Shahar, McGovern, Sprafka, Pankow, Doliszny and Luepker (1995), Bonita, Broad and Beaglehole (1993) and Wolfe (1996) for suggested causes of this decline.

Some (though not all) studies from different countries have suggested that there has been a decline in stroke incidence (eg Ueda, Teruo, Hirota, Takeshita, Katsuki and Tanaka, 1981; Whisnant, 1984; Broderick, Phillips, Whisnant, O'Fallon and Bergstralh, 1989; Tuomilehto, Rastenyte, Sivenius, Sarti, Immonen-Raiha and Kaarsalo, 1996). However because this decline is offset by a decline in mortality (Warlow et al, 1996) and an increase in the ageing population, stroke will continue to be common. Malmgren, Bamford, Warlow, Sandercock and Slattery (1989) estimated the number of people having a first-ever stroke to increase by about 30% between 1983 and 2023.

2.1.3 Effects of stroke

Stroke is the largest single cause of severe disability in England and Wales, with over 300,000 people being affected at any one time (Martin, 1988; Stroke Association, 2002). According to Rudd (1996), half the people who survive the first four weeks after stroke will have a significant disability. Wade et al (1985) suggested that there is an 'almost infinite range of possible permutations and combinations of loss' related to cognitive, communicative and physical functioning. Some of the common longer-term effects of stroke, reported in the general stroke literature, are now briefly described. Because aphasia is a major focus of this thesis, this is discussed in greater detail.

Cognitive problems

Because many stroke survivors are old, their cognitive abilities and memory may have declined as part of the ageing process, which make it difficult to ascertain what difficulties in these functions are due to stroke. However, cognitive and memory problems are considered a common effect of stroke, making day to day living difficult. For example Warlow et al (1996) found 15% of patients in the OSCP to have a significant cognitive defect. In a review of three surveys, Wade et al (1985) found confusion in 45% of those studied in the post-acute stage.

Hemiplegia / hemiparesis

Hemiplegia (weakness down one side of the body) and hemiparesis (paralysis) is common in the long term post-stroke, affecting leg and arm mobility. Skilbeck, Wade, Langton-Hewer and Wood's (1983) study found the majority of recovery in walking ability to occur within the first three months. 81% in their study and 85% in Wade and Langton-Hewer's (1987) study were walking independently at six months, suggesting a sizeable number of stroke survivors remain unable to walk unaided in the longer term.

Arm function, vital for activities of daily living (ADL) such as dressing, shaving and bathing, has been found to recover less well than leg function. Wade et al's (1985) study found 36% of 92 people had no arm function at six months. Wade (1994 cited in Wolfe 1996) reported that at six months, almost 50% needed help with bathing, and 31% with dressing.

Visual disorders

Although older stroke survivors may have age-related visual difficulties, stroke can result in problems such as hemianopia (loss of visual field), visual neglect (failing to notice stimuli from one side) and visual agnosia (difficulties in visual recognition) (Warlow et al, 1996). Reported incidence of visual disorders varies, for example hemianopia was reported in 7% by Wade et al (1985) and in 63% by Gray, French, Bates, Cartlidge, Venables and James (1989). However, they create a variety of problems, including reading difficulties, ignoring food on one side of the plate or failing to attend to anything on the affected side of the body. They can therefore make ADL, leisure, interactional and rehabilitation activities troublesome.

Epilepsy

Figures from the OCSF suggested that those with a first ever stroke had a 2% risk of epileptic seizure – a fit – at stroke onset, and an 11% risk in the first five years. Epilepsy can affect memory, intellectual ability and can result in cognitive deterioration (Thompson, 1997). Risks of seizures and their implications for safety mean epilepsy impacts on daily activities such as driving and sport (Oxley and Smith, 1991).

Apraxias

The apraxias can be described as a range of complex disorders involving motor functions, in which patients are unable to carry out voluntary movements despite being alert, orientated and having preserved motor and sensory function (Wade et al, 1985).

There are different types of apraxias, for example motor, ideational, constructional, speech and dressing (see Wade et al, 1985 for full descriptions). However, central to them all is difficulty integrating available sensory information and motor control. This creates problems with daily life, such that speaking, dressing and preparing food can be rendered impossible.

Emotional effects

Emotional effects of stroke have been defined in various ways and have encompassed mood disorder (Gordon and Hibbard, 1997), depression (Wade and Langton-Hewer, 1987), generalised anxiety disorder (Astrom, 1996) and emotional lability (House, Dennis, Molyneux, Warlow and Hawton, 1989). Because they can be considered a psychosocial effect of stroke *per se*, as well as having a psychosocial impact, these are reviewed more fully in Chapter 2.3.

2.1.4 Aphasia

Aphasia has traditionally been defined as the loss or impairment of language function caused by brain damage, which is manifested in difficulties in understanding, talking, reading and writing² (Darley, Aronson and Brown, 1975). Stroke is the predominant cause of aphasia, and it occurs acutely in about a third of stroke survivors (Wade et al, 1985). Aphasia is often associated with weakness or paralysis of the dominant side of the body, and can be accompanied by the range of impairments already described. The majority of recovery in aphasia occurs in the immediate months following stroke: Skilbeck et al (1983) reported most recovery to occur in the first three months. Although improvement can continue over a long period, aphasia rarely resolves completely, so although acquired suddenly, difficulties are typically long-term and intractable (Sarno, 1993).

There is no doubt that communication difficulties experienced by people with aphasia are a result of neurological damage. However, in recent years the traditional view of aphasia as solely the inevitable consequence of an individual's impairments has been challenged. For example, social model theorists and clinicians view communication disability as stemming from the failure of the social and physical environment to take account of the individual's needs. (This model cannot be considered in more detail here,

² The term 'aphasia' is now widely used to refer to both 'aphasia' (inability) and 'dysphasia' (partial loss). It is used thus in this thesis.

but see Jordan and Kaiser (1998) and Pound, Parr, Lindsay and Woolf (2000) for full exploration). We now have new understanding of the different perspectives and meanings of aphasia, and a broadening of its definition. The two developments most pertinent to this thesis are now discussed.

Aphasia as masking competence usually revealed through conversation

A PWA loses to a greater or lesser degree his³ ability to communicate. Spoken communication, ie conversation, is central to most people's lives: Schifffrin (1988, p272) describes conversation as 'a vehicle through which selves, relationships and situations are talked into being'. Linguistic impairments can compromise a PWA's ability to engage successfully and easily in conversation, and can therefore severely impact on his self-image (Brumfitt, 1985) and feelings of competence (Kagan, 1995). Kagan (1995) recognised that traditional definitions of aphasia failed to capture the central role that conversation plays in people's lives. She extended the definition of aphasia as:

'an acquired neurogenic language disorder that masks competence normally revealed through conversation' (p20).

Inherent in Kagan's definition is the notion that PWA retain competence in many areas of their lives, such as the ability to capitalise on premorbid cognitive and social skills, but that this competence is hidden, or masked, by the presence of linguistic difficulties associated with aphasia. She stated:

'When a person has a difficulty in talking and understanding what is said, it is hard to see the active mind; it is difficult to envisage the capacity to make life decisions, and it is difficult to regard the person as a social being. These perceptions affect the way one is treated.' (p17)

The final sentence in the above quote concurs with Block and Yuker's (1979) finding that the self image of people with disabilities is affected by other people's behaviour towards them, and vice versa (Jordan and Kaiser, 1996).

³ To avoid the use of the clumsy 'he/she', 'he' is used throughout this thesis to refer to a PWA where a choice of pronoun gender could be given. This is justified because all bar one PWA featured in this thesis are male.

Aphasia as affecting personal relationships

This thesis agrees with Kagan's inclusion of 'conversation' into the definition of aphasia, and agrees that conversation is central to people's lives and relationships, as apparent from Schifffrin's (1988) statement above. Conversation is obviously not an individual endeavour, but a social event involving two or more people who co-construct meaning through their talk (Goodwin, 1995). The dual nature of conversation led Goodwin (1995, p255) to also challenge the traditional definition of aphasia thus:

'As an injury, aphasia does reside in the skull. However, as a form of life, a way of being and acting in the world in concert with others, its proper locus is an endogenous, distributed, multi-party system.'

From this viewpoint, the linguistic impairments of aphasia impact not *only* on the PWA, but on his conversational partners, ie the people with whom he has a relationship. This implies, therefore, that both the PWA *and* his partner are required to adapt their patterns of interaction in order to participate in conversation. These patterns may be quite different to those they had before the onset of the PWA's language difficulties (Milroy and Perkins, 1992; Goodwin, 1995; Perkins, 1995; Wilkinson, 1995; Wilkinson, Bryan, Lock, Bayley, Maxim, Bruce, Edmundson and Moir, 1998; Lock, Wilkinson and Bryan, 2001).

The fact that people use conversation to construct and define their relationship has already been discussed. However, this notion has been further developed by Maynard and Zimmerman (1984, p302), who pointed out that the relationship between people can be viewed as 'something that is subject to the ongoing step-by-step management within talk rather than a state of affairs that underlies their talk'. On considering the implications of this insight, and that of Schifffrin (1988) for aphasia, it is possible to see how changes in partnerships' interaction, necessitated by linguistic impairments of aphasia, may create strains on how they construct and maintain their relationship through conversation.

Boles and Lewis (1999) captured the essence of the effect that aphasia – along with the physical disabilities of stroke – has on relationships:

‘Stroke resulting in chronic aphasia and/or physical disability has the ability to disrupt the status quo of and absolutely forces change within relationships: the relationship has aphasia.

2.1.5 Summary

Stroke commonly results in a range of neurological impairments for the PWA, which create difficulties in everyday living activities. Aphasia causes communication challenges for both the PWA and his conversation partners. These have the capacity to change relationships. A more extensive account of the effects of stroke for PWA and their partners is presented in the following sections.

2.2 The study of psychosocial issues in PWA and their partners: definitions and context

This section explores the meaning of ‘psychosocial’ as it has been defined, conceptualised and evaluated within aphasiology. It provides a definition of ‘partner’, considers partners’ roles in care giving, and introduces the importance of psychosocial research for partners.

2.2.1 Psychosocial: a definition

One of the difficulties associated with research about psychosocial issues is the lack of clarification of what is meant by ‘psychosocial’ (for examples and exploration of the wide range of perspectives that have been subsumed under the term, see Gainotti, 1997; Herrmann, 1997). However, this thesis broadly adopts Byng, Pound and Parr’s (2000) useful wide-ranging categorisation, which captures psychosocial effects resulting from aphasia for both PWA and partners. They consider:

- a) effects on lifestyle, including employment, finances, leisure, social networks and social inclusion
- b) effects on the person, including psychological effects, effects on identity, self concept, self-esteem and stigma
- c) effects on others in the immediate social context, including effects for family members on identity, relationships, psychological effects and role change.

2.2.2 Partners: a definition and roles

In this thesis, 'partner' is defined as the PWA's primary conversation partner. This may be the spouse, but could also be a relative who lives with or most regularly visits the PWA. Herein the term partner is synonymous with 'carer'. This is in recognition of the fact that partners of stroke survivors frequently become their primary care-givers, though also in acknowledgement that partners become carers as a direct result of the stroke or aphasia.

2.2.3 Psychosocial research in aphasiology: historical context

Although the psychosocial reintegration of PWA has been a goal of SLT for some time, it has also long been recognised as a problematic aspect of aphasia research and rehabilitation (Hyman, 1971). Until relatively recently, research and therapeutic endeavour has focused almost exclusively upon neurological, neuropsychological and neurolinguistic impairments of the PWA (Howard and Hatfield, 1987). This has led to a skewed perception of needs and priorities (Sarno, 1993) and an incomplete understanding of the consequences of aphasia for everyday life and upon which to develop appropriate programmes which provide support and aim to improve quality of life (Wahrborg, 1989). The relative dearth of psychosocial research has been related to conceptual, practical and methodological problems, which are discussed throughout the following sections. However, the last decade or so has seen a growth in the body of literature on various psychosocial effects of aphasia (for example Anderson, 1992; Brumfitt, 1993; Sarno, 1993; Le Dorze and Brassard, 1995; Jordan and Kaiser, 1996; Le Dorze, Brassard, Larfeuil, Allaire, 1996; Gainotti, 1997; Parr et al, 1997; Code, Muller and Herrmann, 1999; Byng et al, 2000). This has begun to lead to changes and developments in the methods and goals of aphasia research and rehabilitation, and a growing recognition that aphasia affects more than the person who has it.

2.2.4 The importance of partner research

Although there has been a natural tendency in clinical practice and research to focus on the problems of PWA (Christensen and Anderson, 1989), interest in the psychosocial challenges faced by their partners and families has also developed recently. This has stemmed from an increasing awareness that aphasia and its related physical impairments transform not only the psychosocial lives of PWA, but also, by virtue of their relationship with the PWA, the lives of partners and family members (for example, Carnworth and Johnson, 1987; Anderson, 1992; Anderson, Linto and Stewart-Wynne,

1995; Parr et al, 1997; Cant, 1999; Servaes, Draper, Conroy and Bowring, 1999; Tompkins, Spencer and Schulz, 1999). The importance of researching partners' needs and interventions that address them was perhaps confirmed by a clinical forum dedicated to the topic in a 1999 issue of the journal *Aphasiology* (Servaes et al, 1999), to which the reader is pointed for a general overview of recent academic thinking.

Both government and service providers have acknowledged that family caregivers constitute the backbone of caring in the community and assume the 'unremitting burden' of care responsibilities (Twigg, Atkin and Perring, 1990). Decreased lengths of stay in hospital, deinstitutionalisation of people with chronic disabilities and limited alternatives to family care have resulted in family relatives, particularly spouses, having little choice about becoming the main source of full time care and support for stroke survivors (Quereshi and Walker, 1989; Anderson, 1992; Addington-Hall, Lay, Altmann and McCarthy, 1998; Smith and Schwirian, 1998). A two-year longitudinal community study found over 75% of stroke survivors to be living in the community with their co-resident or everyday carers after a year. In 85% of these cases, the carer was a spouse, with the largest group of carers being wives (Wade, Legh-Smith, Langton-Hewer, 1986). With medical advances extending the lives of stroke survivors, and with resources continuously dwindling, the number of family care-givers, and the stresses upon them, is considered likely to rise consistently in future years (George, 2001). Department of Health policy makers now emphasise the need to support and consult with carers (Department of Health, 2001).

Many carers, particularly those living with the dependent person, cope essentially single-handedly (Office of Population Censuses and Surveys, 1988). There is now a wide body of literature demonstrating a host of negative emotional, physical and social effects resulting from assuming responsibility for the care of a dependent elderly and/or ill family member (for example, Horowitz, 1985; Hart, 1990). More specifically related to this thesis, studies referring to caring for people after stroke in general, head injury and dementia shed light on the psychosocial effects of caring (see for example Horowitz 1985; Brody 1990; Schulz, Visintainer and Williamson, 1990; Greveson, Gray, French and James, 1991; Anderson, 1992; Payne and Ellis-Hill, 2001). It is acknowledged that some of the experiences and needs of partners in these groups, the latter two in particular, may be similar to those of partners of PWA. Others are likely to be different, particularly in terms of dealing with behavioural and cognitive difficulties (Draper,

Poulos, Cole, Poulos and Ehrlich, 1992; Gainotti, 1997). However, because some research has suggested that care giving is influenced by factors that ‘transcend disease categories’ (Raveis, Siegel and Sudit, 1990, p58), studies from this wider literature will be featured in this review where that related to stroke or PWA is sparse.

Research about the psychosocial effects and needs of partners living with and/or caring for PWA is still relatively rare. Most of what exists has been carried out in tandem with that about PWA. Some has attempted to address the differences between living with a person with stroke with or without aphasia. Little, however, has addressed the needs and experiences of partners in their own right. This situation is mirrored in many studies of family care giving, and may be because care giving is viewed as a dynamic process in which characteristics of both members of the dyad are important (Hicks Patrick and Hayden, 1999). However, although the psychosocial functioning of and changes for PWA and their partners are closely inter-linked, they can also be considered to be separate (Nichols, Varchevker and Pring, 1996). From a large London-based study of stroke survivors and their carers (reviewed more fully later), Anderson, 1992 concluded that the experience of stroke is different for stroke survivors and their carers in terms of attitudes, expectations, health and changes in daily life. He suggested that both groups are profoundly affected by stroke, but in different ways and at different times, with, consequently, different needs for information and support. In a review of research comparing spouses’ and PWAs’ perceptions of communication and psychosocial problems, Le Dorze and Brassard (1995) concluded that many studies have found little difference between them (see, for example, Malone, 1969, 1970; Helmick, Watamori and Palmer, 1976; Mulhall, 1978; Kinsella and Duffy, 1980; Muller, Code and Mugford, 1983; Herrmann and Wallesch, 1989). Le Dorze and Brassard noted, however, Shewan and Cameron’s (1984) observation that although PWA and their families agree about certain communication-related problems, they do not necessarily agree on the degree to which such problems are bothersome. This suggests that the degree of psychosocial handicap may well be different for each person involved in a relationship and therefore a consideration of each person’s perspective is warranted. Indeed, Le Dorze and Brassard’s own (1995) interview study (reviewed more fully later) found aphasia to cause *different* handicaps for the PWA and the person close to him. They suggested that the reason their conclusion differed to that of previous research was because earlier studies described the attitudes and needs of spouses *in*

relationship to the rehabilitation of the PWA, rather than trying to identify how the spouses were themselves affected by the aphasia. They stated (p252):

‘Relatives and friends are ... affected in a particular manner by aphasia... How they are affected is not reflected in their attitudes, however, as much as in their daily life experience of coping with aphasia. Therefore, it should follow that these persons should not merely be considered as partners in rehabilitation. They may in fact require specific attention for dealing with their problems. Failure to attend to their problems may also lead to further handicaps for both the aphasic person and his or her family and friends. Our subjective impression... is that spouses are particularly affected by aphasia, and more so than other types of relatives/friends. In future work it would be useful to identify the interaction between the handicaps experienced by the relative/friend and the nature of the relationship with the aphasic person.’

To date, such interactions, let alone their component parts, have not been fully identified or explored. It is hoped that this thesis will contribute to the development of knowledge in this field.

A few studies have attempted to evaluate the effect of SLT-facilitated intervention on partner’s psychosocial state. The importance and outcomes of this research are considered in Chapter 2.5.

2.3 The psychosocial effects of stroke and aphasia for the PWA

This section provides an overview of the range of psychosocial changes experienced by PWA reported in literature to date. It does not aim to provide a systematic and comprehensive review and criticism of available studies. Rather, in recognition of the systemic links between partners and PWA, it aims to offer sufficient contextual background from which to understand partners’ experiences, which are described later. In order to do this, the range of psychosocial issues presented in the most pertinent literature has been summarised into five psychosocial domains. These are:

- i) situations of communication
- ii) emotions and the person
- iii) spousal and family relationships and roles
- iv) social relationships and activities
- v) professional and economic life

Each domain is now discussed as a discrete entity for sake of clarity, but it can be seen that they are inter-related and influence each other.

2.3.1 Situations of communication

Unsurprisingly, aphasia results in a range of psychosocial changes related to communication. Some of these were introduced in Chapter 2.1.4. PWA have reported greater effort, fatigue and frustration in conversations. This is as a result of their own difficulties in speaking or understanding, but also of others trying to speak for them or failing to make adjustments for them during conversation (Le Dorze and Brassard, 1995; Parr et al, 1997). People may by-pass the PWA during conversation, even if he is capable of responding. Aphasia may be perceived as a mental illness, dementia or drunkenness. All of these, which reflect stigmatisation, may cause uneasiness, a change of self-image and embarrassment for the PWA (Le Dorze and Brassard, 1995).

Kagan (1995) illustrated the link between the effects of aphasia on conversation and other psychosocial domains. She suggested that linguistic difficulties mean that many PWA have a greatly reduced ability and opportunity to participate in conversation. This affects opportunities for the PWA to reveal and have acknowledged his inherent competence, which further reduces access to conversation and thereby participation in social and community life. This negative cycle can have profound consequences for mental and social health and for perceptions of the self. The latter is discussed further in the next section.

2.3.2 Emotions and the person

Effects of aphasia on the person are wide-ranging and profound. They include depression, and changes to self-image. These are now briefly described.

Depression

For the purpose of this thesis, it is not necessary to discuss the different views on aetiology or pathogenesis of post-stroke depression (though see House, Dennis, Warlow, Hawton and Molyneux, 1990; Wahrborg, 1991; Herrmann and Wallesch, 1993 and Lafond, Joanne, Ponzio and Taylor-Sarno, 1993 for full description and discussion). It is sufficient to appreciate that depression is considered a common effect of stroke - the reported incidence varies from 25% to 79% (Gordon and Hibbard, 1997) - and that this impacts on other domains of the PWA's psychosocial life. Depression has been related to the degree of physical disability and loss of social contact (Gainotti, 1997) and to spouse attitudes (Zraick and Boone, 1991).

Changes to self-image

In this thesis, 'self-image' encompasses self-identity, self-concept and self-esteem. Because these terms are used interchangeably in the literature (Marsh and Hattie, 1996; Ashmore and Jussim, 1997), they are briefly defined here (though for a full theoretical discussion see Baumeister (1995), and for a more in-depth review of self in relation to aphasia see Walshe (2002)).

Self-identity can be defined as 'a cluster of meaningful definitions that become attached to the body, including a name, social roles, membership of various groups, and various other attributes' (Baumeister, 1995, p52). Important to self-identity are the body, social identity and the self as an active agent in decision making. Identity is based on feelings of personal sameness and we are considered to become 'depersonalised' when events or circumstances threaten that (Rosenberg, 1987). Having an identity is a pre-requisite for social interaction. Verbal communication is strongly linked with identity (Fransella, 1972; Brumfitt, 1993; Duchan, Maxwell and Kovarsky, 1999).

Self-concept is a collection of self-knowledge and self-conceptions (ie beliefs about ourselves) formed through personal experiences and interpretation of the environment (Markus and Nurius, 1987). Self-concept involves how we think of ourselves now, in the future and in the past. Self-concept is relatively stable but it is susceptible to change as new roles, situations or life-transitions are encountered (Demo, 1992), and as a result of change in interpersonal relationships (Baumeister, 1995).

Self-esteem is one of the core features of self-concept. It is the generalised or global evaluation of the self. Direct experiences that convince people that they are competent are important to self-esteem. Social feedback, particularly appraisal of significant others, is also an important influence, with perceived or actual negative feedback having a negative effect on self-esteem (Baumeister, 1995).

It can be seen that social interaction is important in maintaining a sense of self. From a symbolic interactionist perspective, it is possible to see how communication difficulties affecting social interaction can lead to change in self-image. It is also possible to see how a major event, such as the onset of aphasia, disrupts the self, which in turn can affect social interaction. The personal accounts of PWA emphasise these points (Ireland and Black, 1992; Newborn, 1997; Parr et al, 1997).

In a personal construct study of seven PWA, Brumfitt (1985) found all to construe themselves differently in the present compared with their 'ideal' selves of the past. Similar differences have been found in people following head injury (eg Tyerman and Humphrey, 1984; Wright and Telford, 1996), with people rating their present self more negatively than their past. The literature on chronic illness also emphasises the negative effect of an acquired chronic condition on self-concept, with loss of self being seen as the most fundamental form of suffering.

2.3.3 Spousal and family relationships and roles

Aphasia has been shown to have a profound impact on relationships between spouses, family members and on household activities and roles. Because of the need for care, many stroke survivors have increased dependency on their spouse or family. This may contribute to loss of autonomy for the PWA and increasing conflict and hostility at home (Le Dorze and Brassard, 1995; Parr et al, 1997). Some research suggests that PWA see themselves as more disabled than other stroke survivors and as particularly disadvantaged in terms of the quality of their relationships (eg, see Anderson, 1992). PWA can feel misunderstood by their spouses and have fewer contacts with siblings and other family members (Le Dorze and Brassard, 1995).

Change to roles and responsibilities are frequently cited (Herrmann and Wallesch, 1989; Anderson, 1992; Herrmann, Johannsen-Horbach and Wallesch, 1993; Sarno, 1993; Le Dorze and Brassard, 1995; Servaes et al, 1999). In Herrmann and Wallesch's (1989)

study involving structured and semi-standardised interviews with 20 'closest others' of people with severe non-fluent aphasia, 80% of the PWA were unable to maintain their pre-morbid domestic responsibilities. Role change may lead to disruption of family relations, including loss of authority over children (Le Dorze and Brassard, 1995).

As the impacts noted here are also related to those experienced by partners, they are discussed further in Chapter 2.4.4.

2.3.4 Social relationships and activities

Social isolation, deprivation and changes in social status have been reported as frequent social consequences of aphasia (Anderson, 1992; Herrmann et al, 1993). Social isolation stems from, among other factors, the PWA's lack of opportunity or inclination to visit friends, to travel to social events or to make new social contacts. It also results from friends' and acquaintances' withdrawal (Herrmann and Wallesch, 1989; Lafond et al, 1993; Kagan, 1995; Le Dorze and Brassard, 1995; Jordan and Kaiser, 1996; Simmons-Mackie and Damico, 1996; Papathanasiou, MacDonald, Whurr, Brookes and Jahanshahi, 1997; Zemva, 1999). Lack of money, lack of appropriate facilities for people with disabilities, as well as the individual's own physical impairments, cause as many as 80% to give up former recreational and sporting activities (Herrmann and Wallesch, 1989; Anderson, 1992; Le Dorze and Brassard, 1995; Parr et al, 1997).

2.3.5 Professional and economic life

The vast majority of PWA has to retire (Joussen and Pascher, 1984). Matsumoto, Whisnant, Kurland and Okazaki (1973) reported that only 3% of PWA retained employment, compared with 33% of stroke survivors without aphasia. Only one of 50 PWA interviewed by Parr et al (1997) returned to exactly the same work post-stroke. Factors related to rehabilitation, employer and social structural systems may interact with personal factors (including the person's impairments) to create barriers to stroke survivors' employment (Lock, Jordan, Bryan and Maxim, in press).

Loss of employment results in reduced income, an ensuing increase in financial difficulties and decrease in standard of living, role changes within the family through the PWA's loss of role of breadwinner, and in loss of social contacts (Herrmann and Wallesch, 1989; Herrmann et al, 1993; Jordan and Kaiser, 1996).

2.3.6 Summary

Stroke and aphasia create change in a range of inter-related areas of the PWA's psychosocial life, including situations of communication, relationships with spouse, family and friends, roles and responsibilities, and social and professional activity. These changes can fundamentally alter how the PWA is perceived and perceives himself, with a resulting profound loss of self. It will become obvious in Chapter 2.4 that many of these psychosocial changes experienced by PWA influence those of their partners.

2.4 The psychosocial effects of stroke and aphasia for partners

The previous section explored the psychosocial effects of aphasia on the people who have it within five domains of psychosocial life. Some of those, plus additional domains pertaining particularly to partners, will be used in this section as a framework for examining the reported psychosocial effects of aphasia on partners⁴. The section concludes with an exploration of literature about how partners cope with living with and caring for a PWA and the resulting psychosocial changes they experience.

A review of the literature has suggested that research to date has uncovered psychosocial change for partners that can be incorporated into seven broad inter-related domains. These are:

- i) situations of communication
- ii) psychological and physical functioning
- iii) the partner's attitude towards the stroke survivor
- iv) spousal and family relationships and roles
- v) social relationships and activities
- vi) professional and economic life
- vii) knowledge of stroke and aphasia

Each of these is now discussed. Although the domains are presented separately it can be seen that they interact with and influence each other.

⁴ The terms 'carer' or 'care-giver' will be used in cases where the studies reviewed have used them

2.4.1 Situations of communication

It has been recognised for some time that communication difficulties resulting from stroke play a major role in determining the psychosocial status of partners, as well as that of PWA (Artes and Hoops, 1976; Bernstein, 1980). Through a combination of self-rating scales, questionnaires and interviews, Anderson (1992) studied 173 supporters of stroke survivors (24% of which were wives, 10% husbands, 40% children and 7% siblings; 70% of the supporters were women). Anderson suggested that communication difficulties (rather than reduced activities, emotional distress, attitudes to recovery or burden of care) most affected the quality of relationships between carers and stroke survivors. From interviews with nine supporters of PWA (four spouses and one each of mother, daughter, cousin, niece, friend), Le Dorze and Brassard (1995) reported that irritation, stress and annoyance become part of communicating with a PWA. This was found to result from the PWA being unable to overcome his disabilities, the supporter being unable to satisfactorily maintain communication, or from other people addressing the partner instead of the PWA. They suggested that partners may also perceive a loss of interest in communicating on the part of the PWA. Zraick and Boone (1991) suggested that families usually have had no previous experience or knowledge of the new communication behaviours of the PWA, and that they are therefore poorly prepared to cope. They suggested that the stress resulting from this may negatively influence family dynamics, particularly spouse attitudes toward the PWA. Herrmann and Wallesch's (1989) study's findings disagreed with those above, and suggested that partners were able to adapt their communication to establish a sufficient degree of communication on issues of everyday life. The differences in findings in the studies above may be a result of differing methods used.

Shadden (1999), whose study was unusual in that she was the researcher plus the spouse of the PWA studied, reported that her own fatigue and stress influenced her communication style with her husband. For example, when highly fatigued her style was transactional, that is, essentially didactic and involving closed questions, but became more interactional when she was not stressed. Her finding (albeit from a uniquely individual perspective) implies that communication influences psychosocial outcome, but also that aspects of psychosocial state such as tiredness and stress, impact on communication. These interactions are illustrated further below.

2.4.2 Psychological and physical health

Partners pay a high price for caring in terms of deleterious effects on their emotional and physical well-being (Brocklehurst, Morris, Andrews, Richards and Laycock, 1981) and in many ways may be disabled and handicapped by their partner's stroke (Anderson, 1992).

Various rates of depression or carer distress (ie negative affect in the carer, (McClenahan, 2002)) in caregivers of stroke survivors have been reported, for example ranging from 13% (Wade et al, 1986) to 39% (Carnwarth and Johnson, 1987). Reported rates in partners of PWA in particular range from 36% to 55% (Kinsella and Duffy, 1980; Herrmann and Wallesch, 1989). The wide range of reported rates is likely to reflect factors related to:

- the variety of emotional consequences studied, eg 'mood' (Wade et al, 1986), 'morale' (Bishop, Epstein, Keitner, Miller and Srinivasan, 1986), 'psychological well-being' (Hodgson, Wood and Langton-Hewer, 1996), 'strain' (Bugge, Alexander and Hagen, 1999);
- the range of assessment methods used, eg General Health Questionnaire (GHQ) (Goldberg, 1978) and Wakefield Depression Inventory (Snaith, Ahmed, Mehta and Hamilton, 1971) used by Kinsella and Duffy (1979);
- different definitions of 'carer' and different relationships between people studied, eg between co-residential spousal carers and formal paid carers (eg Brocklehurst et al, 1981; Cantor, 1983; Dennis, O'Rourke, Lewis, Sharpe and Warlow, 1998).

Most of the stroke carer literature is empirically based, and focuses on and suggests the existence of associations between carer distress and aspects of stroke survivor disability, though associations have been variably and inconsistently found (see Han and Haley (1999) for a full review). Some studies have attempted to link emotional change to demographic and other personal variables of the carer. Both of these are now discussed.

Emotional change in partners related to the stroke survivor's disability

Dennis et al's (1998) quantitative study investigated 246 carers of stroke survivors (mean age of 60, 66% women, and 76% spouses) at six months post-stroke. One aim of the study was to identify stroke survivor factors associated with poor caregiver outcomes. They suggested that carers were more likely to be depressed if the stroke survivors were severely dependent or emotionally distressed (as assessed on

standardised measures) themselves. Carers' emotional distress was higher if the stroke survivors had been dependent, had a handicap, a previous stroke or visual field defect before their index stroke. This was also the case if the stroke survivor had symptoms suggestive of a more severe stroke (such as cognitive problems or the inability to walk), leading to a greater likelihood of disability and dependency at six months (also see Carnwarth and Johnson (1987); Anderson, Linto and Stewart-Wynne (1995)). Dennis et al's findings need to be interpreted in acknowledgement of several methodological issues. These include the problems with assessing psychosocial state using questionnaires, an issue which will be discussed more fully in Chapters 2.5 and 4. Another is that only the stroke survivors' impairments were considered, that is, the influence of social, environmental or relationship factors were omitted. Other studies have suggested that severity of the stroke survivor's disability is not associated with carer distress in the chronic post-stroke stages (eg Brocklehurst et al, 1981), and that the relationship between the two is complicated (Horowitz, 1985).

Greater carer distress has been linked to confusion and behavioural problems of the stroke survivor (Anderson et al, 1995), the state of the partnership's relationship and living arrangements (Zarit and Toseland, 1989). At 18 months post-stroke, 30% of the supporters in Anderson's (1992) study said that the stroke survivor's physical dependency, helplessness or lack of recovery was the difficulty which upset them most.

Some studies have suggested that caregivers of PWA suffer more psychologically than those whose partners do not have language difficulties. Kinsella and Duffy's (1979) study of 79 spouses of stroke survivors found that female spouses of people with hemiplegia and aphasia were more poorly adjusted in terms of psychological health, as assessed on the GHQ, than spouses of stroke survivors with no hemiplegia or no aphasia. They also had poorer physical health and marital relationships. Using a 75-item questionnaire, Christensen and Anderson (1989) found a modest significant difference in emotional problems between 11 partners living with an aphasic relative and 11 living without aphasia, finding 36% and 24% respectively reporting that they sometimes had emotional and/or health problems. Problems included losing patience, feeling anxious, irritable and depressed. Over 80% of spouses in both groups reacted to their partner's disability by being overprotective. Habgood and Hesketh (1996) also found this latter finding in a similar questionnaire study.

Several reasons have been put forward to explain higher psychosocial stress in partners of PWA. These include that PWA tend to complain more about their problems, have more frequent temper outbursts and are more critical than stroke survivors without aphasia, and that these are difficult for partners to live with (Artes and Hoops, 1976; Christensen and Anderson, 1989). In Johannsen-Horbach, Wenz, Funfgeld, Herrmann and Wallesch's (1993) small survey of seven relatives of PWA, using rank ordering of symptoms of emotional stress, their PWA's aggression, language deficit, depression and changing moods were reported as most stress inducing. One view is that aphasia might be especially difficult to cope with as it limits the degree to which partners can discuss mundane day-to-day events as well as more profound changed circumstances (Kinsella and Duffy, 1979).

Some research disagrees with the findings that partners of PWA suffer more than others. Habgood and Hesketh (1996) found partners of stroke survivors who did *not* have aphasia to report more negative emotional changes than those living with aphasia. They also found a small majority of partners to state that they rarely or never experienced any emotional changes. Reasons suggested for this finding were people providing socially acceptable responses to questions or avoiding admitting to emotional problems, social support alleviating emotional problems, and living with aphasia over time aiding emotional adjustment.

Living with and caring for a PWA has also been found to affect caregivers' physical health. Whitehall-Smith (1977) found spouses of PWA to have higher blood pressure, more ulcers, more frequent headaches and greater fatigue than spouses of normal controls. She also found that if spouses were encouraged to acknowledge their grief and anger (using transactional analysis), their physical condition and their attitude towards the PWA improved. In her review of the elderly care-giving literature, Hart (1994) reported that some studies, though not all, suggest that carers report higher rates of illness than would be expected in the population norms. Steptoe (1997) suggested that chronic stress can cause illness by lowering the immune status and through changes in health related behaviour.

Demographic and personal factors in emotion change

The relationship between gender and emotional distress of carers has been addressed by relatively few researchers in the stroke care-giving literature, and findings have been

conflicting (Kinsella and Duffy, 1979; Tompkins, Schulz and Rau, 1988; Dennis et al, 1998; Thompson, Bundek and Sobolew-Shubin, 1990). In Christensen and Anderson's (1989) study, for example, females reported more anxiety than males. In the literature on dementia, women in general are reported to experience more burden than men (Cantor, 1983) and wives are reported to initially experience more burden than husbands (Zarit, Todd and Zarit, 1986). Two reviews of elderly care giving found that women carers reported more distress than men (Horowitz, 1985; Hart, 1994). Proposed reasons for gender-specific emotional reactions include: men's under-reporting of their distress; greater support offered to men than women; lowered self-rated physical health by women; women's use of less adaptive coping strategies; women's greater sensitivity to changes in the stroke survivor as a person; (Stephens, Norris, Kinney, Ritchie and Grotz, 1988; Borden and Berlin, 1990; Anderson, 1992). Anderson suggested that it was consistently difficult to tell whether the experience of women carers was due to characteristics common to carers in general, to the stroke survivors, or to the relationship between them, and called for further research in the area.

Stroke-related studies addressing the influence of age suggest conflicting results. Some have found that age is not associated with carer distress (Thompson et al, 1990; Anderson et al, 1995). One found that older carers were less distressed at seven to nine months post stroke but not earlier (Schulz, Tompkins and Rau, 1988). One found older carers to be more distressed on the Hospital Anxiety and Depression Scale (HADS) but not on the GHQ (Dennis et al, 1998). Reviews of the elderly literature also suggest varying results (Horowitz, 1985; Hart, 1994).

The stroke care literature features little on the relationship between kinship and carer distress. In Dennis et al's (1998) study, no significant difference in distress was found between spouse or partner and others. In research related to dementia, Quayhagen and Quayhagen (1988) also found no differences, though Cantor (1983) found that closer bonds created greater strain and therefore spouses were most at risk, followed by children, other relatives, friends and neighbours.

There is also little research related to socio-economic status, though in a review of the frail elderly care-giving literature, Horowitz (1985) concluded that evidence was unclear: some studies reported that higher socio-economic status was associated with greater stress, others found no relationship.

Only a few stroke care-giving studies have considered the effect that pre-morbid relationship has on carer's post-stroke emotional response, and what exists found that this association varied with time post-stroke (Schulz et al, 1988; Tompkins et al, 1988). Some, though not other, papers reviewed by Hart (1994) reported that a positive premorbid relationship ameliorated distress.

As most studies have been cross-sectional, little is known about the changes that may occur with respect to caregivers' emotional state over time (Dennis et al, 1998). However, some researchers have suggested that carers learn and adapt with time, with a reduction in distress. Others have suggested that carers become exhausted and more distressed over time with the 'wear and tear' of care giving (Holbrook, 1982; Wade et al, 1986; Carnworth and Johnson, 1987; Schulz et al, 1988; Hart, 1994; Smith and Schwirian, 1998).

2.4.3 Partner's attitude towards the stroke survivor

While 'attitude' cannot be considered a psychosocial effect of aphasia for partners *per se*, it is included here because partners' attitudes towards the stroke survivor have been found to influence other psychosocial domains of both the partner and PWA. For example, attitudes of family significantly influence the stroke survivor's response to stroke and rehabilitation (Hyman, 1972; Andrews, 1978) and can also determine the stroke survivor's use of and satisfaction with services (Field, Cordon and Bowman, 1983). Weddel (1987) showed that the key relative's degree of hostility, criticism and emotional over-involvement towards the stroke survivor significantly contributes to the severity of post-stroke depression. Gainotti (1997) suggested that while negative attitudes of caregivers are likely to decrease the self-esteem of the PWA, family members who warmly support their relative and assume a realistically positive attitude towards his condition may restore self esteem and increase motivation.

Zraick and Boone (1991) found that spouses of stroke survivors with either fluent or non-fluent aphasia had a significantly greater number of negative attitudes toward their spouses than matched controls. The most prevalent characteristics attributed to the PWA were 'demanding' and 'temperamental', with 'immature', 'worrying', 'nervous', 'confused', and 'inpatient' also being among the top ten characteristics of both groups. These exclusively negative attitudes were not typical of spouses of people without aphasia. People with non-fluent aphasia were viewed by their spouses as less

independent, less compliant and less sociable than their fluent counterparts. Zraick and Boone suggested that this may be attributable to the non-fluent aphasic person's difficulty with finding words and struggle to speak, or possibly due to the presence of hemiplegia, which is a more prevalent concomitant of this type of aphasia.

Le Dorze and Brassard (1995) suggested, however, that partners may have difficulty in accepting the PWA's emotional reactions to stroke and aphasia and in adapting to the changes brought about by aphasia, and they may act with irritation when pre-stroke family conventions are not respected due to aphasia. They may grow to feel differently about the PWA and may distance themselves from their partner in order to avoid tensions in their relationship.

Caregivers' attitudes towards the PWA may enhance problems or tensions, which exist between partners, which tend to increase over time (Le Dorze and Brassard, 1995). Attitudes include over-protection, unrealism, rejection or denial of impairment (Malone, 1969; Malone, Ptacek and Malone, 1970; Kinsella and Duffy, 1979; Christensen and Anderson, 1989), and unrealistic optimism about the PWA's communicative abilities and future improvements (Helmick, Watamori and Palmer, 1976; Muller et al, 1983; Code, Muller and Herrmann, 1999). Kinsella and Duffy (1979) found overprotection and unrealistic expectations among spouses to be a more common response than either rejection of the stroke survivor or retributive guilt feelings. Unrealistic expectations may be the result of spouses underestimating the severity of aphasia and may lead to frustration and depression in the PWA (Zraick and Boone, 1991). Zraick and Boone suggested that negative or unrealistic expectations of spouses have potential for change. They suggested that spouse treatment and support groups may foster more realistic expectations of and attitudes towards the PWA, leading to a more positive relationship between them and their partners.

Despite the findings from the above quantitative studies, Le Dorze and Brassard (1995) found no evidence within their interview data to suggest that caregivers' views reflected unrealistic attitudes. They suggested that this may have been because of the longer post-onset period and the existence of an ongoing relationship between the people in their sample, compared with, for example, those in Malone's (1969) study. They also suggested that the reason that their subjects' statements did not back up such findings is that the experience of aphasia from the point of view of those affected differs from the one that researchers can imagine when designing questionnaires. Hickey (1999)

commented similarly after finding that the spouses in her interview study (using grounded-theory methodology) failed to use the negative attitudes reported in quantitative studies to describe their husbands with aphasia. She attributed these differences to the interview's ability to allow the spouses to talk freely about what was important in their experience, rather than forcing them to respond to words or questions in a survey or questionnaire.

None of the studies reviewed above considered the impact that the partners' general attitude to caring has upon their attitude to the person they care for. Anderson (1992) and Twigg and Atkin (1994) discuss this, however. They suggest that the task of caring for a person with a disability is surrounded by cultural assumptions about who should care, about mutual and family obligations and, particularly when caring is predominantly for older people, about its value and importance for society:

'Caring may be taken on as a 'natural' response to loving someone, as a duty or obligation, or out of guilt and a lack of alternatives. These attitudes to caring will influence responses to the patient's needs and to caring tasks; and they present complex factors mediating between caring and how supporters feel about this.' (Anderson, 1992, p179)

2.4.4 Spousal and family relationships and roles

Loss of emotional support and sense of partnership, severely impaired sexual relations and intrafamilial tension have been reported as a prominent effect on the spouses of PWA, all having the effect of reducing marital satisfaction (Kinsella and Duffy, 1980; Williams and Freer, 1986; Sparkes, 1993). Although there are no figures available for divorce rates between PWA and their partners, those for head injury are as high as 40 to 50% (Smith and Schwirian, 1998).

Anderson (1992) found a clear fall in the frequency with which supporters of stroke survivors reported 'positive' activities and a deterioration in the quality of interaction and relationship with the stroke survivor over an 18-month period post-stroke. He commented that it is this experience of deterioration in family and social relationships which principally distinguishes life after stroke for people with communication impairments and their supporters. He found this to be particularly the case for spouses, and more particularly for wives. 78% of spouses described life as less enjoyable at that

stage, compared with 37% of other supporters. Those who lived with the stroke survivor were considerably (though not significantly) more likely than others to report that they enjoyed life less. Anderson suggested that, in general, it was the relationships before the stroke and the problems caused by the stroke that were a more significant determinant of satisfaction with life after stroke than measures of disability. He suggested that this had implications for support, and that patients and their carers who live together should be a priority group for social and welfare services, especially if the relationships before the stroke were not good.

One of the greatest effects of aphasia on spousal relationships surrounds role change (Malone, 1969). Many partners have been found to have heightened responsibility for tasks and decisions, which had previously been the PWA's. These range from reading and writing for the PWA to managing financial and organisational affairs (Herrmann and Wallesch, 1989; Le Dorze and Brassard, 1995). Female relatives in Herrmann and Wallesch's (1989) study frequently had to delegate their own premorbid household tasks. Role change for the partner may include providing the stroke survivor with practical assistance, such as getting about and bathing. In Anderson's (1992) study, almost one third of supporters described the burden caused by the help and support they were giving as 'moderate' or 'large'. 66% of supporters were spending more time helping the stroke survivor at 18 months post-stroke than they did before the stroke, two thirds of which said that this help caused them some difficulty (not associated with the supporter's age or social class), the most common being tiredness. Spouses were consistently more likely than children to say that helping caused a problem, although none of the differences were statistically significant.

Christensen and Anderson (1989) found a significant difference in role-related problems between partners of stroke survivors with and without aphasia. 77% of those living with a PWA 'almost always' experienced role change, including making medical and financial decisions, assuming dominance in the family and in giving personal care to the PWA, compared with 38% of partners living without aphasia. These authors suggested (p229-230) that the adaptation to role-change for partners living with aphasia is linked to communication difficulties:

'Given the marked impact of greater role adjustment and the communicative deficit of aphasia... it would seem reasonable to conclude

that the inability of these marriage partners to communicate well with each other may serve to make necessary role adjustments more difficult for the unimpaired spouse. We would conclude, as did Artes and Hoops, that the presence of aphasia has a considerable impact on the interpersonal relationships of husbands and wives.'

Habgood and Hesketh (1996), on the other hand, found no significant differences in role change between partners of people with and without aphasia, with 65% of all partners stating that they now 'almost always' played the dominant role in the family. It was not made clear how dominant their role was before the stroke.

It was mentioned in Chapter 2.2.4 that partners and close family relatives often care single-handedly for stroke survivors. Indeed, only 27% of the supporters in Anderson's (1992) study said that stroke had caused problems for *other* members of the family. He suggested that a lack of shared support appears to be a major reason for the stroke affecting the supporter's relationship with other family members and friends.

2.4.5 Social relationships and activities

The social life of partners of stroke survivors with and without aphasia often alters (Malone, 1969; Malone et al, 1970; Artes and Hoops, 1976; Holbrook, 1982, Anderson, 1992). They may have to abandon a number of activities to take care of the person, and thereby lose friends, give up shared and independent leisure activities and abandon plans for holidays (Anderson, 1992; Le Dorze and Brassard, 1995). Anderson (1992) suggested that reduced energy and time for social activities, plus the loss of the stroke survivor as an active social partner, may be an important cause of problems and distress for the partner. He found that restrictions on daily life, particularly those on time and freedom that supporters had for themselves, were the most frequently mentioned causes of burden on supporters, with 20% of them describing their life as severely restricted by stroke. Wives were especially likely to feel this, but, more generally, 41% of people who lived with the stroke survivor reported that their social activities had been severely restricted. 27% of supporters reported that they were enjoying life much less since the stroke. Among the spouses of younger stroke survivors studied by Coughlan and Humphrey (1982), the loss of companionship and interference with social and leisure activities were described as the major reasons for a loss of enjoyment of life.

Some studies have compared the difference in the social impact on partners of stroke survivors with and without aphasia. Artes and Hoops (1976), for example, found that more than 40% of the wives of PWA felt socially isolated, compared with only 16% of non-aphasic brain-damaged patients. Christensen and Anderson (1989) found that 18.2% of their subjects living with a PWA 'almost always' had social problems compared with 11.2% of those living with a person with no aphasia. Herrmann and Wallesch's (1989) study of 20 partners of PWA found that only a small number of them viewed themselves as suffering from social isolation. The reason for this, they suggested, was that they had lived with aphasia for an average of three years and therefore had adapted to altered social circumstances. Similarly, Habgood and Hesketh's (1996) study found no significant differences between partners of people with and without aphasia, with approximately 50% of both groups reporting few social changes. They suggested that for these people withdrawal from social life had begun prior to stroke due to old age and the need for increased support. However, 42% reported a worse social life, possibly due to a fear of leaving the stroke survivor alone, overprotection, or expectations from their relative to stay in. Two of the partners of PWA in their study actually reported a better social life than they had pre-stroke, resulting from freedom from previous restrictions, improved family and other social relationships and an enhanced sense of the value of life. Habgood and Hesketh suggested that partners' own coping strategies and support from family and friends meant that not all people described negative social and emotional change after stroke.

2.4.6 Professional and economic life

The obligation to remain at home to care for the PWA may prevent relatives from continuing to work or take part in vocational courses (Mui, 1992 in Smith and Schwirian, 1998; Le Dorze and Brassard, 1995). Habgood and Hesketh (1996) reported that 23% of the working caregivers in their study had given up work to care for their partners. Anderson (1992) found no evidence to suggest that supporters of stroke survivors with communication impairments were more likely than those without to report changes or restrictions in their work.

Loss of employment inevitably leads to loss of income and the social activities derived from both (Herrmann and Wallesch, 1989). 25% of the supporters in Anderson's (1992) study reported that they had suffered a financial loss since the stroke, in some cases because of a loss of income, but also because of new expense related to travel and

caring. Families often lack knowledge of their rights, available help or how to obtain help which may enable them to supplement their income or get relief from caring, so they may need to return to some form of employment.

2.4.7 Lack of knowledge about stroke and aphasia

Although lack of knowledge in itself is not a psychosocial domain *per se*, lack of knowledge about stroke and aphasia does appear to affect the psychosocial state of partners. It is therefore discussed briefly in this section.

Anderson (1992) suggested that the values and expectations of carers (and of stroke survivors) are affected by more than social position, age, personality, and severity of disability. They are also influenced by more tangible and modifiable conditions, such as level of knowledge and awareness about stroke (also see Bevington, 1985), plus the quality of the contact with health workers and relevant support at home and in the community. The partners in Anderson's study were anxious for information about cause of stroke, risk of recurrence, prognosis and rate of recovery, mental health and social isolation, available services, and what they could do to help themselves. The majority of them felt they had not received this information, or had received no contact with hospital doctors and nurses. They felt they had been ill prepared for the events and experiences that followed stroke.

2.4.8 Coping with caring and psychosocial change

The literature reviewed so far has shown that partners or carers can experience a host of psychosocial changes, including those related to communication, mental and physical health, relationships with their spouse and family, role changes, and in their social and professional lives. These domains interact with and influence each other, and may be further affected by factors such as the partner's attitude towards the stroke survivor, knowledge of stroke and aphasia, as well as to the stroke survivor's post-stroke functioning, and to demographic and personal factors related to the partner. There is little consistency and consensus regarding the existence and nature of the various associations reported, particularly in relation to partners' emotional reactions. There is little doubt though that care-giving and psychosocial change can create stress for partners, and that there are variations in how they respond to this. In order to achieve a greater understanding of these variations it is necessary to look beyond empirical studies, the field of stroke and aphasiology, factors related to the care-receiver's

condition and demographic factors. This section therefore moves on to summarise some of the main theoretical models (and linked empirical work) within the psychological literature that have attempted to explicate the links for individuals between stressors and different psychological outcomes. For example, factors that have been found to influence the degree of stress experienced by carers include individual response to loss and grief, their coping strategies, personality characteristics and availability of social support. These are now discussed.

Loss and grief

Tanner and Gerstenberger (1988) proposed that the psychological and psychosocial reactions of both PWA and their families can be understood and interpreted as resulting from their experience of loss or psychological separation, after which they travel through four stages of a 'grief response'. These stages were adopted from Kubler-Ross's (1969) model of coping with death. While it is acknowledged that partners of PWA are not dealing with physical death, they do experience loss and separation: loss of partnership, social and occupational activity and so on, as already described. The four stages of the grief response, which occur with 'predictable regularity' (Tanner and Gerstenberger, 1988, p81), are denial, frustration, depression and acceptance, each of which is now briefly explained.

Denial can be seen as a psychodynamically induced defence mechanism that buffers psychological pain, primarily anxiety, and exists to delay awareness of the presence and extent of the loss. Frustration results from the person's inability to alter the course of the event (eg stroke) which resulted in loss (eg of ability to communicate with the PWA). Frustration is most commonly manifest in anger, and sometimes in bargaining, say, with God, therapists or physicians. Once the phases of denial and frustration have passed and a person is consciously aware of their loss, a stage of depression is entered. Provided a person does not become fixated at this stage (marked by depression with severity and or duration that exceeds normal limits) and the grieving process has run its course, the person then enters into an acceptance of the loss. This is seen as the goal of grieving, at which point the experience of loss is assimilated into a psychological framework in which the loss is seen as part of a greater, unalterable gestalt.

Stress and coping

The theoretical point of view of Tanner and Gerstenberger (1988) is close to that of Lazarus (1993), who developed a model to account for individual variations in adjustment to stress. He and his colleagues (notably Lazarus and Folkman, 1984) suggested that adjustment following a life event depends more on the subjective evaluation of the event than on its objective characteristics. Any new event initiates a cognitive appraisal, by which people assess the significance of the event for their well being. If the event is considered irrelevant to their plans, values, well being or self-esteem, appraisal ends and no stress is experienced. If however, the event is appraised as threatening or harmful to the individual, it is defined as stressful, and a process of selecting a response appropriate to the event - a coping response - is implemented.

In their review of the stress and coping model as the main one guiding family care-giving studies, Hicks Patrick and Hayden (1999) discuss antecedent, mediating and outcome variables which influence the choice and use of coping strategies. Antecedents, which typically include primary stressors such as the type of disability, presence and nature of maladaptive behaviours in the care-receiver, are postulated to exert direct effects on caregiver outcomes. Mediating variables are those related to background, sociodemographic factors and personal and social network resources, which enable or impede an individual's ability to cope with life's stressors (Holahan and Moos, 1987). Outcome is psychological well being, which can be defined as a subjective state resulting from long-term personality dispositions, general psychopathology and situation-specific stressors.

Coping consists of cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person (Folkman and Lazarus, 1991). At a general level, coping has been broadly defined as any efforts at stress management. Much theoretical and empirical research has focused on identifying and classifying coping strategies, (Moos and Billings, 1982; Lazarus and Folkman, 1984; Pruchno and Resch, 1989), some of which are now summarised.

- **Problem-focused coping**

This involves planning and carrying out actions to improve a situation or find solutions to a problem. Examples of this are active coping, which involves taking steps to try to remove or circumvent the stressor or to ameliorate its effects, and planning, which is the

process of thinking about how best to handle the problem and identifying the action to take.

- **Emotion-focused coping**

Emotion-focused strategies attempt to regulate the emotional distress caused by the stressor, through cognitive or behavioural means. Examples of this are acceptance, behavioural disengagement (ie reduction or ceasing of effort to deal with the stressor), and venting (ie the tendency to focus on and express feelings about whatever distress is experienced). Although emotion-focused strategies can be active, for example, when constructive efforts are made to regulate affective responses to a stressor, such coping is often oriented towards avoiding dealing with the stress source (Holahan and Moos, 1987).

- **Wishful-escapism focused coping**

This involves fantasies about outcome and the person wishing that they could change what happened or the way they felt, or hoping for a miracle. Some research suggests that older adults are more likely to use this strategy when faced with a situation that is perceived as uncontrollable (Blanchard-Fields and Irion, 1988; Lutzky and Knight, 1994).

Most people use both problem- and emotion-focused coping strategies to deal with stress: problem-focused when the situation is amenable to change and emotion-focused when it is not (Folkman and Lazarus, 1991). Strategies that work effectively at one stage may not work later. An example of this is denial, which is considered adaptive in some situations and maladaptive in others (Lazarus, 1993). The empirical literature suggests that active, problem-focused strategies are adaptive and avoidance strategies are maladaptive (Elias, Hutton, Bratt, Miller and Weinstein, 1987; Barusch, 1988; Kendler, Kessler, Heath, Neale and Eaves, 1991). Gender differences in the use of strategies have been reported. Some suggest that women are particularly likely to use wishful-escapism coping mechanisms (Folkman and Lazarus, 1980; Pruchno and Resch, 1989; Lutzky and Knight 1994). Women also use more emotion-focused strategies than men (Labouvie-Vief, Hakim-Larson and Hobart, 1987), as do older people (Folkman, Lazarus, Pimley and Novacek, 1987). Men, and those with higher income and education use more problem-focused coping (Pearlin and Schooler, 1978). Carers have been found to use both problem-focused and emotion-focused coping strategies. The former have

been found to moderate the adverse influence of negative life events on psychological functioning (Pearlin and Schooler, 1978; Billings and Moos, 1981); the latter have been positively associated with psychological distress, perceived burden and duration of care-giving (Billings and Moos, 1981; Killeen, 1990). Carers' choice of coping strategy and how they attempt to manage their perceptions are said to be influenced by the level and types of stressors in a their life.

It has already been mentioned that a person's adjustment to a life event or situation can be influenced by his subjective appraisal of it. Hicks Patrick and Hayden (1999) noted that care giving is frequently appraised as burden, that is, a perception of anxiety, distress and demoralisation is attributed to care-giving. They point to literature suggesting that burden is an important determinant in family caregivers' psychological well being (Brody, 1990; Pruchno, Klebens, Michaels and Dempsey, 1990).

Personality characteristics as a variable in coping

Hicks Patrick and Hayden (1999) suggested that the care-giving model summarised above offers heuristic value, but leaves the stress and coping process poorly explicated. In an attempt to better understand the individual differences in the care-giving process, they added the individual difference variable of personality to the model, viewing personality as 'a collection of stable, habitual ways of interacting with the environment that may be shaped directly and indirectly by stressful life events' (p274). They included only one personality characteristic – neuroticism - in their analysis of self-report surveys and personal structured interviews with 596 carers of an adult child with chronic disability. Results suggested that higher levels of neuroticism were related to higher levels of wishful-escapism coping, perceived stressors and negative well being.

The role of other personality traits in coping has also been considered. For example, Kobasa (1982) speculated that 'hardiness' (personality dispositions of commitment, control and challenge) buffers stress. Holahan and Moos (1985, 1986) have suggested that people with an 'easygoing' disposition are likely to be more resistant to stress and inclined to use active coping strategies rather than avoidance coping. Optimism, ie the predisposition to believe that one will experience positive outcomes in life, has been associated with problem-focused coping strategies in controllable events, and with positive reinterpretation and acceptance for uncontrollable events (Scheier and Carver, 1985, 1992; Aspinwall and Brunhart, 2000). Schulz et al's (1988) longitudinal study of

carers of stroke survivors demonstrated that optimism varied and was negatively associated with depression. They noted a reduction in optimism over time and suggested that this was due to the realisation of the permanence of disability. Perceived self-efficacy, ie the optimistic belief in one's ability to cope adaptively across many situations (Jerusalem and Schwarzer, 1992; Schwarzer and Fuchs, 1996), has been shown to be a significant predictor in coping with stress. People with high self-efficacy are considered to set themselves challenging tasks, have technical and negotiation skills, invest more effort, persist longer at tasks, recover faster from set backs and have a capacity for delayed gratification. High achievement, good health and better social integration is associated with strong sense of personal efficacy, while depression, anxiety, helplessness and low self-esteem is associated with low self efficacy (O'Leary, 1992; Schwarzer and Fuchs, 1996). Zeiss et al's (1999) study of 217 carers of frail or cognitively impaired elderly people found that care-giving self-efficacy was negatively associated with distress. Schulz, Tompkins, Wood and Decker's (1987) study of 67 carers of people with spinal cord injuries found perceived control (as assessed on a non-standard measure) to be associated with less depression, better psychological well-being and higher levels of life satisfaction. Several studies have demonstrated the beneficial effects of programmes to increase perceptions of self-efficacy. For example, they have been found useful in developing people's skills in influencing their behaviour, setting achievable goals and exercising control over difficult situations (Bandura, 1986, 1992; Fisher and Johnston, 1996).

Though none of the studies summarised above have been related to carers of PWA, they suggest that the consideration of personality characteristics should be included in examination of coping. Their findings may also have implications for interventions with caregivers. For example, suggestions that certain personality characteristics may predispose a person towards coping mechanisms that may be less effective than others imply that intervention that attempts to modify individuals' coping strategies may be beneficial for decreasing negative aspects of well-being and burden and enhance personal caring resources.

Social support

Social support is considered to alleviate psychological distress, reduce mortality and morbidity, facilitate recovery and aid adaptation to illness (Lewis, Rook and Schwarzer, 1994). There is a lack of consensus about the definition of 'social support' (Schrader

and Dougher, 1985; Sarason, Sarason and Pierce, 1990) but Wallston, Alagna, DeBellis and DeVellis (1983, p369) usefully describe it as 'the comfort, assistance and/or information one receives through formal or informal contacts with individuals or groups'. The reader is pointed to Wills (1997) for full description of the different perspectives from which social support has been defined and measured.

Sarason et al (1990) suggested that health outcomes are related more to the *perception* of the availability of social support than the reality of it. It has also been suggested that this perception is an inherently stable personality characteristic, and that social skills are essential in mobilising social support, and shyness an obstacle (Schwarzer and Leppin, 1991).

Two broad models of the impact of social support have been posited. The 'main' or 'universal effect' model states that social support is beneficial at all times, that it prevents the stressful event or affects well being independently of the event. In the 'buffering' or 'interactive effect' model, social support is considered to reduce stress appraisal or provide coping assistance to be protective in periods of stress. This implies that those with higher levels of social support will have better outcomes than those with lower levels (Schwarzer and Leppin, 1992).

Cohen and Wills (1985) describe the constituents of social support. These include:

- emotional support: this is affect support, which often includes esteem support (ie other people making one feel valued) and social companionship (ie support received from spending time with others). This is considered to be the most useful type of social support for coping with life stressors (Sarafino, 1994; Wills, 1997). Empirical research with cancer patients has suggested this is the most helpful type of support from spouse, family and friends (Dakof and Taylor, 1990);
- instrumental support: the provision of practical and material assistance, eg money;
- informational support: useful information provided by social contacts, sometimes subdivided into informational and appraisal support. Cancer patients in Dakof and Taylor's (1990) study found this to be the most helpful form of support from physicians.

As with psychosocial research, the research literature related to social support is unclear due to the variety of conceptualisations of the term and problems with measurement.

Most studies report positive outcomes of social support in terms of stress protection. However, some have revealed that unsatisfactory or problematic support may reduce well being more than the absence of support (Rook, 1984) and that feelings of autonomy, self-reliance and control may be lowered through excessive support (Wallston et al, 1983). Depression in carers has been linked to upsetting interactions in the carer's support network (Pagel, Erdly and Becker, 1987). Cutrona (1996) suggested that social support needs to be optimally matched to the recipient's needs for it to be effective rather than cause dissatisfaction or distress.

It has been suggested that social support affects health through various mechanisms, including by providing a sense of security and boosting morale and self-esteem to lead to adaptive coping strategies (Cohen and Wills, 1985). However, not all studies agree that there is an association between social support and physical health (Schwarzer and Leppin, 1989; Henderson, 1992).

In the stroke care-giving literature, there are only a few papers addressing carers' (cf patients') perceptions of the role of social support in carer mood. Hodgson et al's (1996) study (using a social network scale) suggested that informal social support was unrelated to outcome, but Tompkins et al (1988) found an association in the chronic stage post-stroke (ie six months or later). The type of social support offered to carers appears to be important: Thompson et al (1993) found that engaging in social interaction for fun and recreation was most important in reducing the burden of caring in frail older people, and that instrumental or emotional support were ineffective.

Some studies of carers of people with dementia have suggested a positive association between social support and psychological well being (Geroge and Gwyther, 1986; Schulz and Williamson, 1991). Others found no association (Gilleard, Belford, Gilleard, Whittick and Gledhill, 1984). Negative social support has also been associated with carer distress (Schulz and Williamson, 1991).

2.4.9 Summary

Partners experience change in many aspects of psychosocial life as a result of living with or caring for a person whose own life has changed due to stroke, aphasia or other chronic illness condition. Individual reactions to these changes are influenced by more than factors related to the cared-for person's difficulties or variables related to carer

demographics. Those related to loss and grief, individual perceptions of stressors, coping strategies, personality characteristics and social support are also influential.

2.5 SLT intervention for the psychosocial needs of partners

This section provides an overview of SLT intervention involving partners of PWA. It discusses the importance of researching this area yet illustrates conceptual, practical and methodological factors which have contributed to a dearth of literature. Pertinent existing studies are reviewed within one of four perspectives that can be seen to represent different clinical perceptions of partners.

2.5.1 The importance and difficulties of researching SLT intervention for partners

The previous section illustrated the range of psychosocial changes experienced by partners and family carer-givers, assistance for whom has been urged frequently (eg Christensen and Anderson, 1989; Anderson, 1992; Herrmann et al, 1993; Habgood and Hesketh, 1996; Herrmann, 1997; Dennis et al, 1998). Anderson (1992), for example, stated that advice, information, support and encouragement should be at the centre of strategies to enhance the quality of life of carers of stroke survivors. He called for policy initiatives to increase the volume and acceptability of respite care, family support groups, financial support and appropriate housing. He also stated the need for systematic involvement of staff from health and social services in preparing families for the future, making appropriate use of available resources, transferring skills in caring and rehabilitation, and in helping them to maintain family relationships. More recently, the importance of providing carers with long-term support has been recognised among government and health service policy-makers. For example, the term 'carer' has now become formalised within government policy documents such as the Carers (Recognition and Services) Act (Department of Health, 1995). The needs of carers of stroke survivors are considered in the National Service Framework for Older People (Department of Health, 2001).

Some research has suggested that living with a stroke survivor who has aphasia has a greater negative impact on the partner or caregiver than when no aphasia is present (see Chapter 2.4). This implies that that partners of PWA may be in particular need of help (Christensen and Anderson, 1989), and that SLTs' knowledge of aphasia mean they are

well-placed to contribute to services for them. Several authors have recommended the provision of intervention such as counselling, psychological support, educational programmes and skill training. The aim of these is to help partners come to terms with the PWA's communication difficulties and behavioural change, to adjust to social, emotional and role adjustments, and ameliorate the various problems associated with the life changes aphasia brings (Bernstein, 1980; Brocklehurst et al, 1981; Bevington, 1985; Williams and Freer, 1986; Rice, Paull and Muller, 1987; Christensen and Anderson, 1989; Wahrborg and Borenstein, 1989; Anderson, 1992; Habgood and Hesketh, 1996; Servaes et al, 1999). Such work may require the development of new skills or techniques by SLTs (Mulhall, 1978; Brumfitt, 1993), and a shift from a medical to a psychosocial model of illness after the acute phase of emergency medical care. Some see this as equally important as increasing the sophistication of language assessment and treatment for the PWA (Bernstein, 1980; Anderson, 1992).

Despite the call for the development of services to address the psychosocial problems faced by families of PWA, there is a dearth of reported systematic attempts to provide and evaluate services (Rice et al, 1987; Sarno, 1993; Nichols et al, 1996; Herrmann, 1997; Pound and Parr, 1997; Pound et al, 2000). Various factors may account for this. Some of these relate to SLTs' knowledge and skill base: while elaborate models and evaluation procedures exist for linguistically orientated therapy, concepts and therapeutic procedures for the psychosocial management of PWA and family members are incomplete and fragmented (Herrmann, 1997). SLTs may therefore not feel skilled enough to stray from the technical analysis and treatment of language disorders which for so long has dominated clinical training and practice in order to offer psychosocial support for partners (Brumfitt and Clarke, 1983; Brumfitt, 1993). Even when SLTs feel sufficiently skilled, their response to carer need may be hindered by growing constraints on public expenditure, which in turn are bound to have an impact on research in the field (Anderson, 1992). They may also be hindered by issues of professional boundaries.

Both lack of research and the disparate evidence for the success of the few programmes reported in the literature have been linked to conceptual and methodological difficulties. For example, different definitions and concepts of 'psychosocial' and differing or unclear research questions and hypotheses have led to lack of comparability and replicability of studies (Murphy, Dingwall, Greatbatch, Parker and Watson, 1998; Pring,

1999; Servaes et al, 1999). Evaluation is increasingly seen as an essential part of any health or social service intervention, and omitting evaluation is seen as irresponsible (Reinharz, 1994 in Murphy et al, 1998). However, there are disparate views of what comprises evaluation and its definition, and a lack of suitable evaluation measures (Murphy et al, 1998; Olswang, 1998). One challenge stems from increasing health service demands for quantified outcome measures, which is hard to meet because of problems in quantifying the effects of psychosocial intervention. Despite that, experimental studies, ie those from a researcher's perspective and quantitative in nature, have been favoured and increasingly demanded for evaluating carer interventions (Pring, 1999; Servaes et al, 1999; Tompkins et al, 1999). In such studies, variables such as individual differences, programme variability and measurement stability are controlled by the researcher or clinician. Randomised control trials have been suggested as desirable (Pring, 1999). However, it is often impossible to achieve any or all of the necessary controls over goals, inputs and output measurements or to maintain control groups (Murphy et al, 1998). There are also uncertain ethics and impracticalities of assigning participants to intervention and non-intervention groups. It has been suggested that evaluations involving control of the individual sources of variance may gloss over the important differences between intervention participants and fail to reveal the various ways in which they may benefit (Pound, Parr and Duchan, 2001). In reality, most studies have been small group or single-case studies. While such design is likely to reflect clinical reality (Marshall, 1998), results are considered not representative or generalisable to a whole population, and statistical data may be unreliable or difficult to interpret (Herrmann, 1997).

Questionnaires have dominated studies involving assessment of psychosocial state in stroke carer and aphasiology research, and in evaluations of the effects of carer programmes (Mykyta, Bowling, Nelson and Lloyd, 1976; Bowling, 1977; Bevington 1985; Rice et al, 1987; Wahrborg and Borenstein, 1989; Zraick and Boone, 1991; Johannsen-Horbach, Crone and Wallesch, 1999; Pound et al, 2001). Examples of those used in studies pertinent to this thesis include the GHQ (Goldberg and Williams, 1988), HADS (Zigmond and Snaith, 1983), Beck Depression Inventory (Beck, Mendelson and Mock, 1961), Wakefield Depression Inventory (Snaith et al, 1971), Illness Perception Questionnaire (Weinman, Petrie, Moss-Morris and Horne, 1996), and Sickness Impact Profile (Deyo, Inui and Leininger, 1982). The popularity of questionnaires stems from their being relatively quick to administer, thus minimising burden for the person and

clinician completing them. They are often standardised and are able to provide quantifiable scores amenable to statistical analysis and hence generalisation (Fitzpatrick, Davey, Buxton and Jones, 1998). However, they can be considered problematic on several grounds⁵. Perhaps most importantly, they provide information about psychosocial issues which is decontextualised. They are intended to capture a very broad range of aspects of health state (Fitzpatrick et al, 1998) and so cluster issues together under broad headings, for example 'emotional problems'. It is not possible to see what importance the person places on the individual issues or how each contributes to the result (for example, see Christensen and Anderson 1989). They do not allow for expression of individual needs or issues, and fail to take account of complex changes in a person's social and personal circumstances (Pound and Parr, 1997). Specifically in relation to caregivers, Twigg and Atkin (1994) note growing criticisms of the use of objective, quantitative measures for being detached from how people cope with their lives and for using pathologising language which does not reflect how many carers perceive their situations. In terms of their use as outcome measures, despite being used as objective evidence some suggest that measures that require self-report actually address the person's subjective experiences, which cannot be objectively 'verified' (Fitzpatrick et al, 1998). Assessments of psychological well-being, in particular, were often developed to measure inter-patient differences for purposes of diagnosis rather than as outcome measures, and they may therefore be inappropriate and not sensitive enough to demonstrate changes over time (Fitzpatrick et al, 1998). For a fuller critique of quantitative measures than is possible to provide here, see Fitzpatrick et al (1998).

The recognised difficulties in evaluating the psychosocial effects of intervention obviously must be overcome if research endeavours in this field are to move forward. The need for new research was illustrated by Rice et al's (1987, p247) comment which, though dated, holds true today:

'There is a desperate need to collect evidence to demonstrate the best approaches to use in providing intervention for spouses suffering severe psychological stress. Only in this way will it be possible to develop successful and well-tried techniques in providing psychological care.'

⁵ For consideration of issues about using questionnaires with PWA, see Ross, 1983; Code, 1987; Bryan; 1989; Starkstein and Robinson, 1988; Code and Muller, 1992).

The remainder of this chapter reviews the evidence so far and reviews a range of research involving partners. Only those studies which have specifically addressed the effect of intervention on partners' psychosocial state are reviewed in-depth.

2.5.2 SLT intervention for partners: literature review

The idea of SLTs working with the partners of PWA is not new. As far back as the 1950s clinicians were encouraged to involve partners in the therapy of the PWA, with the rationale that partners interact with the PWA in everyday life and so provide opportunities for the reinforcement and generalisation of skills outside of the clinical setting (Wepman, 1951). More recently, however, therapists have begun to work with partners in ways which have involved the development of different types of relationship between themselves and partners. Jordan and Kaiser (1998) suggested that these relationships can be usefully conceptualised by using the typology of agencies' perceptions of informal carers, developed by Twigg (1989) and Twigg and Atkin (1994). Having adapted this typology for the purposes of this thesis, clinicians and intervention research can be seen to view partners from four different perspectives. These are:

- i) partner as a *resource*
- ii) partner is *superseded*
- iii) partner as a *co-worker*
- iv) partner as a *co-client*

These four perspectives are introduced below and utilised as a framework for examining a range of SLT service-facilitated interventions involving partners of PWA.

Studies within which the partner is viewed as a *resource*

Therapists may see partners as a resource for the PWA, as Wepman (1951) above. In such a relationship, the partner's needs are disregarded and it is assumed that there are no conflicts of interest between the PWA and the partner. This is the traditional relationship that clinicians have had with partners, and is particularly linked with impairment-based approaches to diagnosis and therapy. These are not considered further in this thesis.

Studies within which the partner is *superseded*

The therapist may aim to supersede the carer, either to relieve carer burden or, in the case of intervention studies within aphasiology, to empower the PWA by promoting his or her independence. Lyon, Cariski, Keisler, Rosenbek, Levine, Kumpula, Ryff, Coyne and Blanc (1997), for example, showed that pairing PWA with trained volunteers for community-based activities resulted in statistically significant gains for the PWA in informal measures of well-being and communication. Similarly, Kagan (1998) and her colleagues have developed a programme entitled Supported Conversation for Adults with Aphasia. This provides PWA with the opportunity to engage in a conversation with volunteers with the aim of reducing the psychosocial consequences of aphasia. Though evidence for the effectiveness of these approaches, which move towards a socially motivated model of intervention (Simmons-Mackie, 1998) is to date primarily anecdotal (Marshall, 1998), their success is likely to lie in the central role which conversation plays in every-day life (Schiffrin, 1988; Kagan, 1995) (see Chapter 2.1.4).

Authors whose work with PWA supersedes partners have suggested that spouses may not be the best person to provide the PWA with opportunities for conversation in cases where relationship difficulties existed either prior to the aphasia or have developed since its onset. However, most PWA and their partners live together and need to communicate and manage their relationship on a day-to-day basis: superseding the partner does nothing to actively promote this. Addressing partnerships' communication and relationship issues seems particularly pertinent in the light of the withdrawal of social contact after stroke and the fact that many couples are left to cope alone.

Studies within which the partner is viewed as a *co-worker*

Partners or caregivers may be seen as co-workers in providing a service to the PWA, in that any service offered to the partner is given in order to maximise the PWA's welfare. For example, some researchers have recognised that therapeutic care provided for family members influences the success of the stroke survivor's rehabilitation (Boisclair-Papillon, 1993; Herrmann, 1997). Jordan and Kaiser (1998) cite an example of the partner being viewed as a co-worker when offered a place in a relatives' support group, so that any resulting benefits to his or her mental health might also benefit the PWA, perhaps by reducing the amount of stress in the household. Another example of partner as a co-worker can be found in Simmons, Kearns and Potechin (1987). They demonstrated in a single case study that it was possible, through training, to change

aspects of a spouse's conversational style to enable her partner with aphasia to contribute more to conversation. The result of the partner being taught to reduce interruptions and questioning was that the PWA used increased number and length of verbal responses during conversation, even though he was not directly targeted in the treatment.

More recent attempts at training partners in conversation skills highlight further the benefits for the PWA of providing partners with individualised, specific advice about communication (Lesser and Algar, 1995; Booth and Perkins, 1999; Booth and Swabey, 1999). These studies have also begun to explore the use of conversation analysis (CA) techniques to inform and provide a framework for offering that advice. CA can be defined as a qualitative procedure for analysing both the verbal and non-verbal aspects of naturally occurring interaction, eg conversation between partners. (See Hutchby and Wooffitt (1998), Damico, Oelschlaeger and Simmons-Mackie (1999) and Lock et al (2001) for readable introductions.) Conversation data is transcribed using a system developed to focus particularly on aspects of interaction which have been shown to be of particular importance in conversation. Aspects which appear particularly relevant to aphasic conversation, and which are described in depth in Lock et al (2001) are:

- trouble and repair, ie the methods used by speakers to deal with a variety of troubles in speaking, hearing or understanding (Schegloff, Jefferson and Sacks 1977; Jefferson, 1987; Milroy and Perkins, 1992; Wilkinson, 1995; Wilkinson et al, 1998; Lindsay and Wilkinson, 1999);
- turns and sequences, ie the ways in which people construct turns during conversation and how people adapt their turns in the presence of aphasia (Schegloff and Sacks, 1973; Lesser and Milroy, 1993; Perkins, 1995);
- topic, ie the initiation and maintenance of subjects of conversation (Atkinson and Heritage, 1984; Button and Case, 1984).

Lesser and Algar (1995) combined findings from CA and cognitive neuropsychological tests of two women with aphasia to establish strategies which their caregivers were then trained to apply in order to facilitate communication with them. This programme of 'indirect intervention achieved through caregivers' (p67), ie the therapist working with the carers in their own homes, provided advice through verbal explanation and a personalised booklet about their PWA's type of stroke and aphasia and specific word-

finding difficulties, the repair patterns apparent from the conversation analysis, and potential repair strategies. Results of the study suggested that the caregivers valued the individualised advice and had acted upon it. The percentage of facilitative repair strategies they used increased after the advice, although the proportion of those which were successful in effecting repairs did not reach statistical significance. Similarly, Booth and Swabey (1999) provided four carers of adults with aphasia with a communication skills programme, using CA to guide individualised advice about each partnership's patterns of collaborative repair. Their intervention was also based on results from the Conversation Analysis Profile for People with Aphasia (CAPPA) (Whitworth, Perkins and Lesser, 1997), which utilises CA as a means of both characterising and comparing the relationships between the carers' perception of the aphasia and what is occurring in natural conversation. Booth and Swabey offered their programme in a group setting, during which accurate perceptions and strategies which minimised disruption to conversation were reinforced, while inaccurate perceptions and strategies which appeared to impede interaction were discouraged. Results from the study were not conclusive but suggested that the carers' perceptions of different aspects of their relatives' aphasia appeared to improve. Although the overall decrease in problem severity reported by the carers on the CAPPA was not found to be significant, there was a move in a positive direction for all of them. One participant in particular appeared to have adapted his conversation to facilitate swifter repairs during conversation with his brother with aphasia (also see Booth and Perkins, 1999).

It can be seen from the studies above that the approach of working on partnerships' patterns of conversation, through the application of CA techniques, has the potential to create change in the real-life interactions of PWA and their partners. Because the PWA does not have to be part of the programme for change to be achieved, and because such intervention seems to lend itself to being provided in a group situation, such an approach may be popular with resource-limited, cash-strapped service providers (Cunningham, Bremner and Boyle, 1995).

Jordan and Kaiser (1998) discussed the vested interest that clinicians may have in working with partners as co-workers. They suggested that the assumption inherent in this model is that partners are expected to want to care and to possibly sacrifice their own needs for the good of the PWA. However, it may be that by working on conversation, certain needs of the partners are indeed met. The centrality that

conversation plays in everyday life and the links between conversation, relationships and psychosocial state were discussed earlier. Because of these links, it is possible that working on the conversation skills of the partner not only facilitates communication for the partnership, but in so doing, facilitates their relationship together and thereby their psychosocial well being. If this was the case, such an approach could claim to be working with partners as both co-worker and co-client (see next section), and therefore offer additional positive outcomes for clients and clinicians, and increased cost-effectiveness. None of the CA studies to date has considered this issue, though this thesis aims to do so.

Studies within which the partner is viewed as a *co-client*

When partners are viewed as co-clients, the clinician acknowledges that partners have needs of their own and are worthy of services in their own right. Partners may be offered services which aim to ease the burden of caring and improve their welfare. This form of intervention may result in services being diverted from the PWA, but may actually be in his or her longer-term interest (Jordan and Kaiser, 1998).

There are few studies in the aphasia literature which have reported on SLT intervention for partners as co-clients. There are fewer still which have attempted to assess their effect on the partner's psychosocial state, though those that have done so are reviewed in-depth below.

The earliest studies from this perspective focused on the provision of support or education in a group setting. Rice et al (1987) reviewed those undertaken by authors such as Bowling (1977), Bernstein (1980) and Bevington (1985), and reported that most of the early studies comprised either clinicians' subjective reports of their experiences of offering intervention, used informal assessment measures, or provided no clear pre- and post-intervention measures. A closer look at Bevington (1985) illustrates their point. Bevington provided a group of 17 relatives of stroke survivors with aphasia, dysarthria or dyspraxia who were in-patients of a rehabilitation centre, with a structured education programme. The programme focused entirely on the provision of knowledge, via a video, a lecture and a booklet. She used a multiple-choice questionnaire to compare the group's post-programme knowledge of stroke and its effects on communication with the knowledge of a group of 13 relatives who did not participate in the programme but received instead 'traditional ad-hoc counselling'. Results suggested

that the knowledge of the programme participants was significantly greater. However, because the questionnaire was not administered prior to the intervention, it is not possible to determine whether their prior knowledge or that gained during the programme was responsible for the result. Other factors, such as the range of relationships to the PWA (eg spouse compared with child), the time post-stroke and the range of disorders the relatives were dealing with, were not considered. The effect of the programme on the relatives' broader psychosocial state was not explored.

Rice et al (1987) pointed out that, despite the methodological difficulties with the studies they reviewed, they did highlight the value of including an educational aspect to programmes for relatives, and also the potential benefits of providing such information through support groups. These authors recognised the growing use around that time of support groups for families of people with disabilities such as multiple sclerosis, Parkinson's disease and dementia. They also noted a related growth in clinical interest in the philosophy underpinning such groups. They stated, for example, that the general aim of such groups is 'to provide information, to initiate the learning of coping strategies and to develop an atmosphere of trust to foster the development of psychological well-being' (p248).

Rice et al (1987) used the early research findings as a basis for their own study, which, they claimed was the first of its kind to objectively demonstrate that participation in a support group can be of psychological benefit to spouses of PWA. In their study, ten spouses of PWA (ranging from between two- and 23-months post-onset) joined a short-term fixed-contract structured programme (one evening per week for two hours, for 12 weeks). The programme aimed to provide information, enhance psychological adjustment and to initiate strategies to improve functional communication. It included observation of videos developed by two stroke/aphasia charities, free sessions in which issues proposed by the group were discussed and visits by professionals (eg a physiotherapist, a psychologist). This intervention for the spouses was given 'in the context of providing normal therapeutic support for the aphasic partner' (p248), although the form this took was not stated. Rice et al began the study without a control group, the reason for which was to give priority to participants' clinical needs. However, they used four poor attenders, who had attended the group for a mean number of two sessions, as a control for six good attenders, who attended for a mean number of 10.5 sessions.

Evaluation of the effects of the group was by two measures of psychological well-being, on which the spouses were assessed on three occasions: 'before the group formally met, towards the end of the group's existence, and some 6-10 weeks after the group terminated' (p251). The first measure was the GHQ-60 questionnaire (Goldberg, 1978), a self-administered screening test to detect minor psychiatric disorders. Significant differences were reported between good and poor attenders. For example, on the GHQ's scale of social dysfunction there were no significant differences between them before the group began, but there was a significant difference six to ten weeks after the group had finished. Only good attenders showed significant improvement on this scale from first to final assessment. The findings on the somatic scale and anxiety scale were similar for both groups, except that poor attenders' scores significantly worsened from the first to second assessment. On the severe depression section all subjects had very low scores at first assessment and no significant changes occurred throughout the study.

The second measure was the Personal Questionnaire Rapid Scaling Technique (PQRST) (Mulhall, 1978). Rice et al described this as offering 'an objective means of scaling psychological well-being through the use of idiographic measures' (p250). They chose the measure because, although not used widely other than in studies pertaining to mental health, it was felt to be sensitive to *individual* changes in attitudes and the ways in which people perceive issues. Its administration involved participants being interviewed to identify and record ten statements that reflected their feelings or attitudes about important issues in their lives. These statements were then rated adjectivally to gain information about the feeling intensity, and the idiographic data was then used to produce a nomothetic measure for each statement, which was used to monitor change. The PQRST therefore appeared to have the capacity to provide something of an 'insider perspective' on psychosocial state (ie data chosen by each individual), and therefore to overcome the limitations of questionnaires described earlier, as well as quantitative results for outcome measurement purposes. Rice et al did not, however, describe the individual aspects of the assessment, they merely stated that they found six statements that were common to all spouses and four that were unique to each. They did not specify how they organised the numerical data for statistical analysis, though results they provided suggested they used T-tests to compare the total 60 statements from the good attenders (ie ten statements from each) with the total 40 statements from the poor attenders. On this basis, their results suggested no difference between good and poor attenders prior to the programme, but significant improvement for good attenders and

deterioration for poor attenders at second assessment, which took place towards the end of the group. A significant difference between the groups was also found at the final assessment point six to ten weeks after the group had finished. Only the good attenders significantly improved from the first to final assessment, but because no comparison was made between the second and final assessment, it is not known to what degree the effects of the programme were maintained.

Rice et al concluded that their results strongly suggested that regular participation in a support group was of psychosocial benefit to spouses of PWA. They also tentatively suggested (from results of functional communication assessments with the PWA) that working with partners helped the functional communication of the PWA. However, they urged caution in the interpretation of their results because of the difficulties inherent in the study. They acknowledged the absence of a formal control group, and that changes could have been a result of differential rates of spontaneous recovery. Given that four PWA were four months or less post-onset, this may be possible. They did not, however, acknowledge several other factors which may have influenced their results. First, it is possible that the therapeutic support that the PWA continued to receive during the study may have influenced their own and thereby their spouse's outcome. Second, because they only provided one baseline assessment it is not possible to say with any certainty that improvements occurred because of the programme. A double baseline may, for example, have shown change outside the period of intervention. Third, although an improvement in PQRST scores was noted six to ten weeks after the group had finished, this may have been a result of participants continuing to meet informally after the group had finished rather than as a lasting effects of the group.

The authors discussed the value of the two measures they employed. They used the GHQ 'primarily to enable findings in the study to be related to similar studies emphasising individual adjustment' (p254), though they did not actually discuss how their findings related to others. They stated that the GHQ provided an appropriate and effective way of obtaining a number of easily analysable scores, which was not the case for the PQRST, the data from which required 'restructuring and to some extent altering in order to produce scores' (p254). Indeed, their manipulation of numerical data in order to undertake statistical analysis provided only broad brush-stroke results, which force the reader to wonder what might have been 'lost in translation'. The authors acknowledge the fascinating personalised data produced by the PQRST, but because

none was included in the paper, the individuals' psychosocial issues could not be accessed. This seems a waste of an assessment method designed to facilitate this. Criticisms aside, Rice et al's study provided some evidence that offering partners support and information in a group setting has the potential for positive effect on psychosocial state. It is just not possible from their paper to tell what that effect was, a limitation which the first and second studies of this thesis aims to overcome.

Rice et al recognised the need for future studies to look for trends regarding the relationship between different aspects of improvement, such as the suspected relationship between psychological well being in spouses and improvements in the functional communication of their PWA. They also highlighted the importance of trying to ascertain whether it is the content of group programmes that are of value to participants, or the group itself. The first two studies of this thesis attempt to address that need.

Another study which included family members of PWA as co-clients was that of Nichols et al (1996), which evaluated the use of family therapy techniques. While family therapy is beyond the scope of this thesis, methodological aspects of Nichols et al's study are reviewed here because of issues they raise about psychosocial evaluation.

Nichols et al's comprehensive review of related intervention studies suggested conflicting results and descriptive rather than evaluative reporting of outcomes (such as from Rollin, 1984; Borenstein, Linell and Wahrborg, 1987), a finding which mirrors Rice et al's observation of studies about carer support/education groups. They attributed this to difficulties inherent in evaluating complex therapies (family therapy and group-work included). They noted, for example, that family members can present with symptoms which may imperfectly reflect their underlying disorders, and distinguished first-order change (ie a change in symptoms) from second-order change (ie more fundamental change to the underlying difficulties in, for example, relationships within the family). They suggested that while changes in symptoms may be more readily assessed, disagreement exists about whether these necessarily indicate changes in, for example, relationships.

In their own study, which provided intervention using 'family therapy techniques' for two families, Nichols et al (1996) aimed to attempt a degree of synthesis between

qualitative and quantitative methods of psychosocial assessment. Thus the focus and goals of therapy were identified by in-depth interviewing of each family and by agreement between family and therapist. The interviews led to the identification and recording of three of four agreed areas of difficulty for each member of the family. Like Rice et al (1987), the nature and severity of these difficulties were monitored using the PQRST, which they administered at three months and immediately before therapy, and immediately and three months after. They recognised similar benefits of using the PQRST to Rice et al, but, additionally, commented positively on its relatively simple and repetitive use of language, and its use of adjectives to describe feelings rather than numbers or points on a scale. Their use of it addressed some of the limitations of Rice et al's (1987) study, in that they provided information about the psychosocial 'symptoms' identified by participants, enabling the reader to understand something of the issues which were important for individuals. However, they provided no analysis of individual differences in need between various family members or at different stages of the study. They are less clear than Rice et al on their manipulation of the numerical data for statistical analysis, though they appear to have grouped together the statement scores of different family members for comparison purposes. They suggested that the PQRST was capable of identifying symptom change at different assessment points: their comparisons using Wilcoxon tests suggested no change in scores prior to therapy, but significant changes for PWA immediately and three months after therapy. Family members showed no significant change immediately after therapy and only approached significance some three months after. However, they did show overall significant change across the experiment. Nichols et al attributed this finding to intervention being focused predominantly on the PWA's needs rather than those of the family members, and it was therefore not sufficient to help relatives.

Nichols et al attributed the PQRST's ability to identify change to its 'idiographic assessment technique which allowed each person to provide his/her own symptoms' (p775). However, because of their analysis it was not possible to obtain any information about individual responses to the therapy provided. This may have been achievable if the data had been analysed from an individual perspective. This is a consideration of the first study of this thesis.

2.5.3 Summary

Few studies have attempted to systematically evaluate SLT-led intervention addressing the psychosocial needs of partners of PWA. This may be the result of practical constraints and methodological difficulties. Some of these difficulties were illustrated in the review of studies that have offered intervention to partners as co-clients. This focussed predominantly on studies by Rice et al (1987) and Nichols et al (1996). They were the only ones at the time of the CWC project and inception of this thesis which had attempted to objectively evaluate the psychosocial effects of their intervention for partners of PWA in a way which attempted to consider the individual issues faced by the participants. As such, they influenced the design and methods of the first study of this thesis, which is described fully in the following chapter.

CHAPTER 3

STUDY ONE

**The psychosocial outcome of a group support
programme and a group conversation training
programme for partners of PWA:
evidence from the
Personal Questionnaire Rapid Scaling Technique**

Introduction

This study evaluates the psychosocial outcome of two types of group intervention for partners of people with chronic aphasia: a support programme and a conversation training programme. The introduction to the thesis in Chapter 1 describes the background to the study, but the reader is reminded that it is a development of the CWC Project, on which I worked as research SLT. The psychosocial assessment data presented here was analysed by me for this thesis, though results from other measures analysed for the CWC project are summarised herein for contextual purposes. The study also evaluates the research and clinical utility of the PQRST (Mulhall, 1978), the measure used to assess the psychosocial state of the participants.

In the following section, the literature reviewed so far is summarised to provide context for the rationale and aims of this study.

3.1 Summary of literature review, rationale and aims of this study

The literature reviewed so far has suggested that partners experience a variety of psychosocial changes as a result of living with and caring for a PWA, and that there is a recognised need to provide them with assistance to alleviate potential or actual psychosocial distress. Although, because of their skill base, SLTs may be well placed to meet that need, to date there have been few reported systematic attempts to evaluate the psychosocial outcome of SLT-facilitated intervention for partners. Chapter 2.5 highlighted a few studies' findings that suggested that the provision of information and support in a peer-group setting has the potential to bring about positive psychosocial outcomes for partners, though methodological problems in such studies have led to mainly anecdotal or subjective evidence of their efficacy. There is an obvious requirement to extend the clinical knowledge base about the psychosocial outcome of this way of working with partners, using more rigorous research methodology than has been reported to date.

Another, more recently developed intervention for partners, is the application of CA theory and techniques to aphasia intervention. Chapter 2.5 discussed some recent studies that have shown that working on partners' conversation skills has the potential to bring about change in their real-life interactions with the PWA, and to enable

partnerships to communicate together more effectively, even when the PWA is not part of the intervention programme. Because of the suggested links between conversation, relationships and psychosocial experience, it may be possible that a programme that aims to have a positive effect on conversation between partnerships also has the potential to enhance psychosocial well being. If this was the case, such a programme could be seen to provide multiple benefits for both partners and PWA in one cost-effective package. However, no studies to date have addressed this. **The main aim of Study One, therefore, is to evaluate the psychosocial outcome of two types of intervention for partners of people living with long-term aphasia: a group programme of information and support and a group conversation training programme.**

The literature review highlighted some of the problems of evaluating psychosocial outcome. Contributing to these has been the demand for objective measures of symptom change, and therefore the predominant use of standardised outcome measures, most notably questionnaires. It was suggested that these are unsuitable for evaluating psychosocial change or effects of programmes, primarily because they are unable to capture the very individual experiences and needs of partners that arise from caring for a PWA or of participating in intervention. They therefore provide little meaningful information on which to base or evaluate intervention. One measure that has shown the potential to overcome the limitations of questionnaires is the PQRST (Mulhall, 1978). As suggested in Chapter 2.5, its use in previous therapy evaluation studies has shown that it may meet health-service demands for time-efficient, objective outcome measurement, at the same time as providing clinically relevant, idiographic information about individuals' psychosocial state. Because of this, the PQRST was chosen to evaluate the psychosocial effects of the intervention programmes featured in this thesis, despite statistical problems experienced in previous studies as a result of analysing data from a group perspective (Rice et al, 1987; Nichols et al, 1996). An exploration of these problems in Chapter 2.5 suggested that analysing data from an individual perspective might provide more useful information about programme effects for participants. Study One therefore analyses data from group *and* individual perspectives, in an attempt to both provide context for further examination of previous studies and to overcome their limitations. **Another aim of Study One, therefore, is to evaluate the research and clinical usefulness of the PQRST.**

3.2 Method

This section describes the study participants, design of the CWC project and assessment measures, and the group programmes. Hereinafter, the information and support programme is referred to as the Support Programme, and the conversation training programme is referred to as the Conversation Programme.

3.2.1 Participants and practicalities

The focus of this study is 12 partners of PWA who completed the CWC project. This section provides their details. Those of their relatives with aphasia are provided where appropriate to provide as much context as possible about each partnership.

The criteria for the partnerships' participation in the CWC project were:

- Partner: living with PWA, or in daily contact
- PWA: left-hemisphere CVA
6 months or more post-onset
neurologically stable
any age
no general cognitive deterioration, as reported by referee
receiving no SLT for duration of project

All of the PWA in the CWC project had been discharged from SLT services or were on review prior to its start. Partnerships were referred by SLTs from two NHS trusts (who were also involved in post-project management decisions about future care and intervention provision), and from a self-help group for PWA. Tables 1.1 and 1.2 provide pertinent details of the 12 partners included in this study, and contextual information about their PWA. All names have been changed to protect confidentiality.

Table 1.1: Details of the partners included in this study and their PWA

Partner (relationship to PWA)	Age of partner (years)	Months as carer since onset of aphasia	Age of PWA (years)	Neurological history of PWA: number of left-hemisphere CVAs (TIAs): aphasia type
Partners receiving Support Programme followed by Conversation Programme*				
1: Judith (wife)	74	48	74	1 (1): anomic
2: Fatima (wife)	65	8	67	1: anomic
3: Lauren (wife)	62	50	63	1: anomic
4: Tina (wife)	60	57	61	1: Broca's-type
5: Kurt (husband)	73	48	73	2: anomic
6: Carole (wife)	53	35	54	1: Broca's-type
Partners receiving Conversation Programme followed by Support Programme*				
7: Ursula (wife)	65	18	64	1: anomic
8: Amy (wife)	57	12	65	2: anomic
9: Vera (wife)	60	14	63	1: Broca's type
10: Gwen+ (wife)	67	19	67	1: jargon
11: Jenny (daughter)	38	16	77	1 (1): Broca's type
12: Denise (daughter)	48	As 11		

* See text below for explanation of programme order

+ left the programmes after completion of Conversation Programme and post-programme assessment period

Table 1.2: Work situation of partners and PWA before and after PWA's stroke

Partner	work before (and after) PWA's stroke	PWA	work before (and after) stroke
1: Judith	homemaker (same)	Jack	retired milkman (same)
2: Fatima	cleaner (same, but part-time)	Ben	occasional work as translator (retired)
3: Lauren	lecturer/psychotherapist (same)	Bob	horticulturist (part-time college lecturer)
4: Tina	homemaker/part-time administrator (retired from part-time work)	Keith	architect (retired)
5: Kurt	retired salesperson (same)	Megan	retired book-keeper (same)
6: Carole	secretary (retired)	Nick	policeman (retired)
7: Ursula	retired company director (same)	Joe	retired company director (same)
8: Amy	care assistant (retired)	Paul	joiner (retired)
9: Vera	seeking work, attending college course (retired)	Bernard	taxi driver (retired)
10: Gwen	clerical assistant (retired)	Maurice	accountant (retired)
11: Jenny	homemaker (same)	Jerry	retired tax inspector (same)
12: Denise	homemaker (same)		

16 partners began the CWC project and upon referral they were allocated to the first available of two differently ordered programmes. The first four partners referred joined 'Therapy Order 1' (TO1), which was the eight-week Support Programme' (SP),

followed by the eight-week Conversation Programme (CP). One man left after session one because of difficulties leaving work to attend, and one woman left after session three because she was unable to find care for her husband while at the group. This left just two (participants 1 and 2 in the above tables) in the programme, who formed TO1a. Because of this attrition, a second TO1 programme (TO1b) was introduced. Four spouses (participants 3 to 6) started and completed it.

Therapy Order 2 (TO2) consisted of the CP followed by the SP. This ran after the programmes for TO1 had been completed. Five spouses, two daughters of the same father and one volunteer began TO2, but one spouse withdrew shortly after the programme had begun due to difficulties organising care for her husband while she attended the group. Another spouse (Participant 10 on Table 1.1) left the project for personal reasons after completing the CP and post-CP assessment. Her data have been incorporated into this study where possible. The volunteer completed the programmes but has been excluded from this study as it was felt her psychosocial needs would be dissimilar to those of the relatives.

The referral and allocation process to the CWC project was felt to mirror service provision practicalities but resulted in participants in two groups that were obviously not matched. As can be seen from the details in Table 1.1, those in TO1 had generally been living with a PWA for longer than those in TO2. TO2 included two daughters, whereas TO1 comprised spouses only. Also, the aphasia types of the PWA differed. Because the overall focus of the CWC project was primarily on the individual effects of the two programmes rather than on control of variation, these differences were considered acceptable.

The referral and allocation process also necessitated running the programmes in different venues, and dividing the people who participated in TO1 into two sets so that they could access the programmes without travelling prohibitive distances. It is acknowledged that this situation is not ideal from a methodological perspective, but was necessitated by the unavailability of a venue that was suitable and accessible for all participants. Table 1.3 summarises therapy group organisation and venues.

Table 1.3: Details of therapy group organisation and venues

Therapy order	Participants	Venue
1a	1 and 2	Room in university department
1b	3, 4, 5 and 6	Home of Participant 4
2	All participants in TO2	Meeting room of local hospital

3.2.2 Design of CWC Project

The CWC Project design included dual ordering of the Support and Conversation Programmes. This, and the inclusion of multiple base-line and post-intervention assessments was designed to enable the effects of the different programme components to be explored, as described below. Table 1.4 summarises the CWC project design.

Participants receiving TO2 were assessed twice (eight weeks apart) before receiving any intervention. This was intended to serve as a baseline for the evaluation of change during intervention. Although no substantial change was anticipated in this period, any change detected then would be attributable to factors other than those related to the programmes, such as the participants' own attempts to adjust to their problems. Participants were also assessed immediately after the CP and again immediately after the SP.

As well as being assessed immediately before and after the SP, participants in TO1 completed the assessment immediately after the CP and eight weeks after all intervention had finished. This was designed to allow monitoring of the longer-term effects of intervention, though change after the programmes had ceased was expected to be unpredictable (as per Nichols et al, 1996).

In order to prevent the participants from being overloaded by assessments, a decision was made by the CWC team to assess only one set of participants twice at baseline, and one set twice at the end of intervention. The different assessment schedule for the two groups was facilitated by running TO2 after TO1 had been completed.

As previous research has shown that support programmes have the potential for reducing psychosocial distress, and as the SP was designed to specifically address

psychosocial issues, it was hypothesised that significant improvement in psychosocial issues (as reported on the PQRST assessment) would occur after the SP. The outcome of the CP was considered to be less certain, as no previous studies had evaluated the effects of partner conversation training on their psychosocial state. However, given the suggested link between conversation, relationships and psychosocial well-being, it was considered possible that the CP, which aimed to facilitate strategies for more effective communication between partnerships where desired, would also create positive psychosocial change for participants. Assessment after each programme was designed to enable their effects to be evaluated.

Table 1.4: Design of the CWC Project

No. of weeks	TO1 (participants 1-6)	TO2 (participants 7-12)
1-3	Assessment 1 (baseline 1)	assessment 1 (baseline 1)
8	Support Programme	period of no intervention
1-3	Assessment 2	assessment 2 (baseline 2)
8	Conversation Programme	Conversation Programme
1-3	assessment 3	assessment 3
8	period of no intervention	Support Programme
1-3	assessment 4 (maintenance)	assessment 4

3.2.3 The Support and Conversation Programmes

The focus and aims of the programmes are now summarised (for a fuller description see Lock et al, 2001).

Both the Support and Conversation Programmes consisted of eight two-hour sessions. The content of the SP was informed by group programmes reported in the literature, particularly Bevington (1985) and Rice et al (1987). The content of the CP was informed by aspects of CA theory which were most applicable to conversation in aphasia (see Chapter 2.5.2 and Lock et al, 2001). Tables 1.5 and 1.6 show the week-by-week main focus of the programmes. The information and written materials for each session were personalised as far as possible to suit the specific support and information requirements of each partner and the specific conversation patterns of each couple, as suggested by pre-intervention measures, discussed shortly and summarised in Table 1.7.

Table 1.5: Weekly focus of the Support Programme

Week	Focus
1	Getting to know each other and group guidelines (if first session); introduction to stroke
2	Recovery from stroke and recurrence; how the brain organises language; aphasia types
3	Complicating factors co-existing with aphasia; general strategies for helping understanding
4	General strategies for helping understanding and expression
5	Living with aphasia: the psychosocial effects of aphasia on the PWA
6	Living with aphasia: the psychosocial effects of aphasia on partners, family and friends
7	Coping strategies in aphasia: getting help; services and how to access them
8	New developments in aphasia: visit from representative of Action for Dysphasic Adults (a charity for PWA now known as Speakability); recap and social get-together (if final session)

Table 1.6. Weekly focus of the Conversation Programme

Week	Focus
1	Getting to know each other and group guidelines (if first session); conversation and relationships: conversation as collaboration*
2	Explanation of linguistic impairments experienced by PWA in the project; impairments as trouble sources during conversation
3	Repair (i): what is repair; repair strategies used by PWA
4	Repair (ii): repair strategies used by partners; repair as competence and as a choice
5	Turn-taking (i): theory of turn-taking; balance
6	Turn-taking (ii): strategies used by PWA and partners
7	Topic: patterns of topic development/maintenance; topic as power
8	Re-cap; social get-together (if final session)

* For fuller explanation of terminology in this table see Lock et al (2001)

The general subject matter of both programmes was designed prior to the commencement of the groups to allow some degree of control and comparison between them. It was recognised that participants in the SP may raise issues that would be covered later in the CP, and vice versa. However, the therapist aimed to achieve a balance between retaining some control over the major content of the sessions week-by-week and allowing participants to explore avenues of their choice. Participants recognised this as a necessity of the research.

The aim of the SP was to offer partners psychosocial support and information which related as much as possible to their personal situation and needs. It aimed to provide a non-judgemental environment in which to explore and discuss emotional, psychosocial and relationship issues, and to enable the partners to develop or increase insight into the links between those issues and the communication difficulties caused by aphasia. It aimed to facilitate the sharing of ideas and experiences and learning about tried-and-tested or new ideas and strategies for coping, adapting, problem-solving and ultimately living with aphasia. The SLT's roles included:

- facilitating discussions about topics raised during the sessions, either by the participants or the therapist;

- encouraging group members to support each other through the sharing of ideas, issues and concerns;
- providing information which would enable participants to gain a greater understanding of the subjects being covered in the sessions;
- providing opportunities for group members to apply learning to their own situations.

The therapist's shift between facilitator and information provider was dependent on the subject matter and the developmental stage of each group. For example, the aim for the first few weeks of the SP (for those in TO1), was for the therapist to spend a greater proportion of time as information provider. This was designed to allow the participants time and space to gel as a group without feeling pressurised to take part in discussions about issues which may have been perceived as challenging or threatening. It was hoped, however, that after a few weeks into the programme, the participants would feel confident about asserting their own needs, wishes to tell their own stories, and about sharing their experiences and skills. Indeed, at this stage they began to rely more on each other within the group, and less on the therapist, whose role then became primarily facilitative. It should be noted, however, that the therapist's role shifted throughout each session in response to the participants' interactions and reactions.

The aim of the CP was to enable each partner to gain or increase insight into the conversation patterns that they and their relative with aphasia had developed in order to adapt to aphasia, to reflect upon them, and to identify and actively experiment with options for change. To facilitate this, the therapist led the participants through three stages for each area being focussed on, drawing on the theory of experiential learning (Kolb, 1984). These stages were:

- **Raising awareness of conversation in general**

for example, explanation of the general concept of 'overlap' during turn-taking and the reasons behind overlap in aphasic conversation. This stage was facilitated by the therapist showing video examples of conversation and presenting information on handouts as a means of promoting discussion, and by the participants taking part in role-plays and written exercises;

- **Raising awareness of own patterns of conversation**

for example, raising the partners' awareness of their own patterns of overlap during conversation, in order to develop a greater understanding of the effects of this on the partnerships' conversations. This stage was facilitated by the participants viewing and discussing examples from their own conversations that they had videotaped with their PWA, looking at transcripts of these conversations and completing a range of experiential learning activities;

- **Strategies for change**

for example, enabling the partners to come to a decision on whether they would like to retain or change their patterns of overlap during conversation, and to identify, practice and experiment with new strategies. These strategies were identified by the partners themselves, through other group members, through ideas identified through written information sheets or exercises, by doing role-play or through discussion with the therapist. They were given the opportunity to practice strategies within the session and provided with means of recording and reflecting upon their use at home.

Following the reported success of personalised written information by Lesser and Algar (1995), a personalised handbook was provided for each partnership. This was updated each week with written information reinforcing the content of the sessions. Material in the handbook was supplemented by literature produced by charities such as Speakability and the Stroke Association. A full set of literature based on these handbooks can be found in Lock et al (2001).

3.2.4 Measures

A comprehensive battery of assessments was carried out with participants at each phase of the CWC Project, to both inform the intervention programmes and to monitor the effects of the programmes. Although only one of the assessments used, the PQRST, is the focus of this study, description of the other assessments, their administration and results are provided in summary form where appropriate, in order to provide context for the PQRST results. The CWC measures are summarised in Table 1.7.

Table 1.7. Summary of assessment measures used in the CWC Project

Assessment name	Description and focus of assessment	At which assessment points administered
Perception of stroke issues (POSI) scale (specifically designed for CWC Project)	12 questions linked to a visual analogue scale to assess partners' perceptions of knowledge of issues about stroke and aphasia	all
Communicative Effectiveness Index (CETI) (Lomas, Pickard, Bester, Elbard, Finlayson and Zoghaib, 1989)	16 questions linked to a visual analogue scale to assess partners' perceptions of the functional communication abilities of their PWA	all
Comprehensive Aphasia Test (CAT), Swinburn, Porter and Howard, in preparation): linguistic subtests	a range of psycholinguistic screening tests to assess the linguistic abilities and impairments of the PWA	first and final
CAT (Swinburn et al, in preparation): disability / emotions questionnaire	a range of questions linked to visual analogue or rating scales to assess PWA's perceptions of communicative disability / emotional consequences of aphasia	first and final
Conversation Analysis Profile of People with Aphasia (CAPPA) (Whitworth et al, 1997): questionnaire	a series of questions which enabled both partners to discuss their perceptions of their conversation management patterns in terms of turn-taking, topic management and repair	all
Conversation analysis	partners were video-recorded in everyday conversation in their own home. The conversation was transcribed and analysed for patterns of turn-taking, topic management and repair	all
Personal Questionnaire Rapid Scaling Technique (PQRST) (Mulhall, 1978)	Assessment of the partners' psychosocial state	all

The partners' psychosocial state was measured using the PQRST (10-point scale) (Mulhall, 1978). A description of the assessment and its administration in previous studies is provided in Chapter 2.5.2. In order to complete the assessment, an individual interview (lasting between 25 and 60 minutes) between the author and each partner took place, during which up to ten pertinent beliefs, feelings or attitudes about the effect of their relative's stroke or aphasia on psychosocial aspects of their life were identified. The interview was carried out in the partner's home when the PWA was not present. Prior to the interview the nature of the assessment and the procedures for carrying it out were explained, and the participant was given the opportunity to ask questions about it. Discussion was stimulated by asking the partner to think about how their relative's stroke had affected their own life, and how they felt about that. During the discussion,

issues as they were described by the partner were noted. In order to allow the partners to introduce issues important to them, attempts were made not to lead their comments. However, those people who encountered difficulty in identifying which areas were problematic for them, or who had difficulty in describing their feelings about particular issues, were asked facilitative open questions. Examples of these are 'How have things changed since your partner's stroke?', 'What things are different now?', 'How do you feel about your situation since the stroke?'. More focused questions were asked where necessary, such as 'How do you feel about your partner's communication skills?' The prompt sheet used during the interview is provided as Appendix 1A. At the end of the discussion, the issues that had been identified were summarised. The partner was then asked to choose the issues which were most important to her/him and which should therefore be included on the PQRST. Not all partners chose the maximum ten issues. The partner and the author then discussed how each issue should be worded on the questionnaire, as it was necessary to turn the partner's verbatim report into a statement, which could be qualified by an adjective. For example, if the partner said 'I'm worried about dealing with the finances', it was necessary to write the statement down as 'my worry about dealing with the finances is...', so that the partner could then judge the degree of worry during the assessment process and allocate a rating to the statement. An attempt was made to retain the participant's own language as much as possible during this process. On a couple of occasions, partners were able to identify changes to their lives but were not able to easily describe their feelings about those changes. For example, they might say 'I have to deal with the finances now', but could not say how they felt about the situation. On such occasions, the partner was facilitated by having the statement written down with a space left for the feeling to be inserted, eg: 'I am _ _ _ _ _ that I have to deal with the finances now'. The partner was then helped to fill the gap with a feeling by talking about the issue and what it meant to him or her. The issue was then turned into a rateable statement as above.

Having identified the most pertinent issues for inclusion on the PQRST, the partner was given verbal and written instructions about how to self-administer the assessment (as shown in Appendix 1B). The researcher was available to answer questions and clarify, if requested, the meanings and relative intensity of the different adjectives provided. For each issue, six adjectives ('absolutely none', 'very little', 'little', 'moderate', 'considerable', 'very considerable') were presented in different pairs to the partner. Within each pair one adjective implies greater magnitude than the other, and the partner

was required to say which member of the pair came closer to describing her or his current level of feeling about the issue.

The assessment was scored immediately upon completion by the partner. This entailed placing a template provided in the assessment over the score sheet, to enable a numerical score for each issue to be read off. This score was achieved by counting the number of pairs in which the more intense adjective was chosen. For example, if the lesser adjective in a pair was always chosen, the score was 0, if the greater adjective was always chosen, the score was 9. The scoring system highlighted contradictory responses, which could be caused by either a failure of comprehension or lack of attention to the assessment, or the participant's doubt about the exact intensity of the issue. In cases of contradictory responses, the partner was either asked to re-rate the issue concerned, or, in the case of doubts about the intensity of the issue, was asked to state what was intended. The numerical scores obtained from the assessment allowed the intensity of each issue to be monitored at each assessment point. In an attempt to reduce practice effects the issues were presented in a different order each time. An example of the first completed assessment for one participant is provided as Appendix 1C.

3.3 General results from the CWC Project

3.3.1 Attendance at the groups

Most participants attended sessions regularly. Those in TO1 attended for a mean of 7.6 SP sessions, and 7.2 CP sessions. Partners in TO2 attended for a mean of 7 CP sessions, and the five who remained in the project for the SP attended a mean of 5.4 sessions. Contributing to this low final figure were the absences of participant 8 (Amy), who attended only one SP session. The mean number of attendances of the remaining participants who attended this group was 6.25. Table 1.8 shows each participant's attendance at the groups.

Table 1.8: Participants' weekly session attendance

Participant	TO1																	
	SP each week:									CP each week:								
	1	2	3	4	5	6	7	8	Total	1	2	3	4	5	6	7	8	Total
1: Judith	√	√	√	√	√	√	√	√	8	√	√	√	√	√	√	√	√	8
2: Fatima	√	√	√	√	√	√	√	√	8	√	√	√	√	√	√	√	√	8
3: Lauren	√	√	√	√	√	√	√	√	8	√	√	X	√	√	√	X	√	6
4: Tina	√	√	√	√	√	√	√	√	8	√	√	√	√	√	√	√	√	8
5: Kurt	√	√	√	√	√	√	√	√	8	√	√	√	√	X	√	√	√	7
6: Carole	√	√	X	X	√	√	√	√	6	√	√	√	X	√	X	√	√	6
Participant	TO2																	
	CP each week:									SP each week:								
	1	2	3	4	5	6	7	8	Total	1	2	3	4	5	6	7	8	Total
7: Ursula	√	√	√	√	√	X	√	√	7	√	√	√	√	√	X	√	√	7
8: Amy	X	√	√	X	√	√	√	√	6	√	X	X	X	X	X	X	X	1
9: Vera	√	√	√	√	√	X	√	√	7	X	√	√	√	√	√	√	√	7
10: Gwen	√	√	√	√	√	√	√	√	8	left project before start of programme								
11: Jenny	√	√	√	√	√	√	√	X	7	√	X	√	X	√	√	√	√	6
12: Denise	√	√	√	√	√	√	√	X	7	√	X	√	X	√	√	√	√	6

3.3.2 CWC project assessment results

In order to provide an overall picture of the different outcomes of the partners' participation in the programmes, and to provide context for later discussion of the PQRST results, a broad summary of the most pertinent results from the CWC project assessments is provided in Table 1.9. The PQRST results obtained during the present study are also summarised thereon.

It can be seen on Table 1.9 that all participants showed significantly improved scores on the POSI scale and the CETI after the first programme component they attended. None of the PWA showed any linguistic improvement as a result of their partner attending the programmes, though some (particularly whose partners participated in TO1) suggested they felt less disabled in terms of understanding/talking by the end of the project. Only two partnerships showed changed conversation patterns after the CP. Fuller descriptions of the assessments, their analysis and results (other than PQRST) can be found in Wilkinson et al (1998) and Lock et al (2001). The PQRST results are discussed in detail below.

*Table 1.9: Summary of profiles of change for participants in the CWC Project; assessment point/s at which statistically significant change occurred compared with previous assessment (as judged by Wilcoxon signed-rank tests), ie after baseline (B), after SP, after CP, after maintenance period (M), or overall (O) across the study (as judged by Friedman test). All changes are positive unless marked with *, which indicates negative change. Blank boxes in table indicate no change*

Partner (months living with aphasia)	Partner felt s/he knew more about stroke, aphasia and conversation (as rated on POSI Scale)	Partner felt that PWA's functional communication abilities had improved (as rated on CETI)	PWA showed changed linguistic patterns (on CAT linguistic sub-tests)	Conversation analysis showed changed conversation patterns (not statistical change)	PWA showed change in feelings of disability in talking and understanding (as rated on CAT disability sub-tests)+	PWA showed change in negative emotions relating to aphasia (as rated on CAT emotional consequences sub- test)+	Partner showed psychosocial change (ie change in PQRST scores when analysed from individual perspective)
Participants in TO1							
1: Judith (48)	SP, CP	SP, M		CP	final		
2: Fatima (8)	SP	SP, CP					
3: Lauren (50)	SP	SP			final		
4: Tina (57)	O	O			final		CP, O*
5: Kurt (48)	SP	SP			final*		SP, M*
6: Carole (35)	SP, CP	SP					CP, M*
Participants in TO2							
7: Ursula (18)	B, CP, SP	B, CP		CP			SP
8: Amy (12)	CP, SP	CP					SP
9: Vera (14)	CP, SP	O					SP
10: Gwen (19)	CP	CP					
11: Jenny (16)	CP, SP	O			final	final*	
12: Denise (16)	CP, SP	M					

+ PWA were assessed twice only, at the first and final assessment points

3.4 The effects of the programmes on partners' psychosocial state as suggested by PQRST results

The effects of the SP and CP upon the psychosocial state of the participants, as assessed on the PQRST, are described below from both a group and individual perspective.

Before considering the results, it should be remembered that it was decided to attempt a group analysis of the quantitative data in order to follow up the analytical approach used in previous evaluation studies (Rice et al, 1987 and Nichols et al, 1996), and thus enable a degree of comparison between their results and those in this study. It was recognised that such an analysis was less than optimal, and that statistical analysis of individual data sets would be more appropriate. This was therefore also carried out, and, as will be seen, this analysis revealed something very different to that from the group perspective. This should be borne in mind when considering the data now provided.

3.4.1 PQRST results from a group perspective

In order to judge the psychosocial effects of the SP and CP on participants in both therapy groups, the PQRST scores from the individual statements of each participant in TO1 were combined into a single data set, as they were for participants in TO2. This occurred for each assessment point. Rice et al's (1987) and Nichols et al's (1996) findings suggested they used this method of data reduction. It is recognised that an alternative would have been to analyse a mean rating across statements for each participant, but this was not possible due to the different number and content of statements provided by individuals. SPSS (the Statistical Package for the Social Sciences) was used for all statistical analysis. All significance levels are 2-tailed unless stated otherwise.

Participants in TO1

All who participated in TO1 completed the PQRST at each of the four assessment points: before intervention, after the SP, after the CP, and eight weeks after the CP had finished. A Friedman test was used to judge the overall effect of the programmes. This showed a statistically significant change in scores over the period of the project (chi-square 15.57; $p=.001$). In order to analyse at which point in the programme this change occurred, a comparison of the participants' mean scores at each assessment point was made using Wilcoxon signed-rank tests. These showed a significant decrease in scores (ie a decrease in symptom severity) from assessment point one to two. This could be

taken to indicate that the SP had had a positive effect on participants' psychosocial state. There were also significant differences in scores between assessment points one and three (baseline compared with after the CP) and points one and four (baseline compared with after the eight-week period of no intervention). There were no significant differences between points two and three (after the SP compared with after the CP), two and four, or three and four. These results indicate that the PQRST scores were significantly lower at each point compared with the first assessment, but that they did not decrease significantly further after the SP. There was a slight (non-significant) trend for the mean scores to continue to decrease after the CP, and for them to begin to increase again at assessment point 4, once the programme had been over for eight weeks. The mean PQRST scores and results of the Wilcoxon tests are found in Tables 1.10 and 1.11 respectively, and scores are displayed in Figure 1.1.

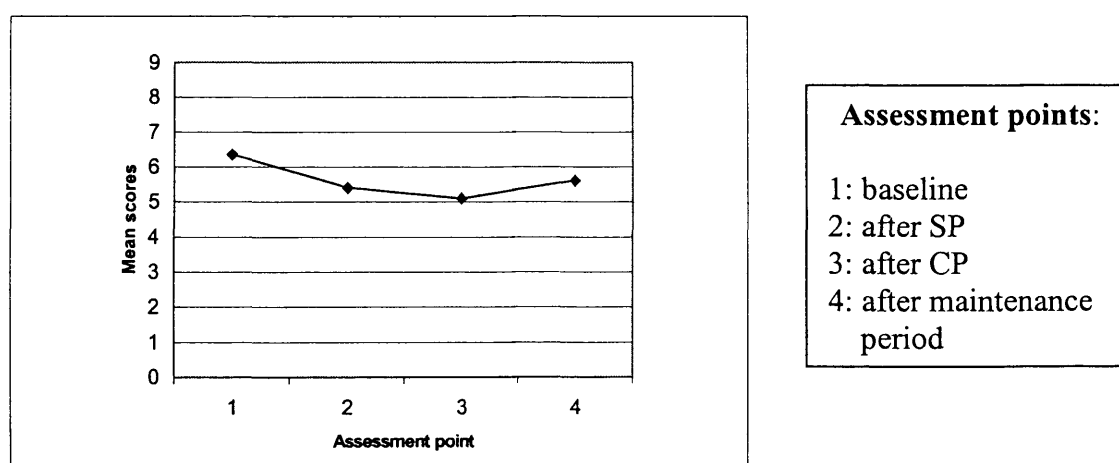
Table 1.10: Mean PQRST scores from a total of 46 statements rated by six participants in TO1 at each assessment point

Assessment point	Mean score	Standard deviation
1 (baseline)	6.35	1.64
2 (after SP)	5.39	1.84
3 (after CP)	5.09	2.09
4 (maintenance)	5.59	1.53

Table 1.11: Wilcoxon tests showing comparisons of scores from total of 46 statements rated by six participants in TO1 at different assessment points (statistically significant improvements in bold)

	Wilcoxon tests comparing scores at assessment points :					
	1-2 (baseline-after SP)	1-3 (baseline-after CP)	1-4 (baseline-after maintenance)	2-3 (after SP-after CP)	2-4 (after SP-after maintenance)	3-4 (after CP-after maintenance)
Z	-2.474	-3.368	-2.264	-1.228	-.815	-1.859
Sig	p=.013	p=.001	p=.024	p=.220	p=.415	p=.063

Figure 1.1: Mean PQRST scores for participants in TO1 at different assessment points



Participants in TO2

Five out of the six participants who took part in TO2 completed the PQRST at all four assessment points. For these participants there were two baseline assessments before intervention, one after the CP, and one immediately after the SP. The data of participant 10 is not included in this analysis, as she completed only three assessment points. Analysis mirrored that for TO1. A Friedman test showed a statistically significant change in scores over the period of the project (chi-square 22.530; $p=.000$). Wilcoxon signed-rank tests showed no significant change in scores between assessment points one and two. This could be taken to indicate that the partners' psychosocial state, as reflected in the issues rated on the PQRST, remained stable between baseline assessments. Again, the manipulation of data for analysis should be considered when

interpreting these results. There was also no significant difference in scores between assessment points one and three (first baseline compared with after the CP), or between points two and three (second baseline compared with after the CP). This could indicate that the CP did not affect the participants' psychosocial state. There was, however, a significant decrease in scores between assessment points one and four and points two and four (baselines compared with after the SP), and between points three and four (CP compared with SP). This could indicate that the PQRST scores reflected improved psychosocial state as a result of the SP.

The mean PQRST scores and results of the Wilcoxon tests for participants in TO2 are found in Tables 1.12 and 1.13 respectively. Figure 1.2 displays the scores.

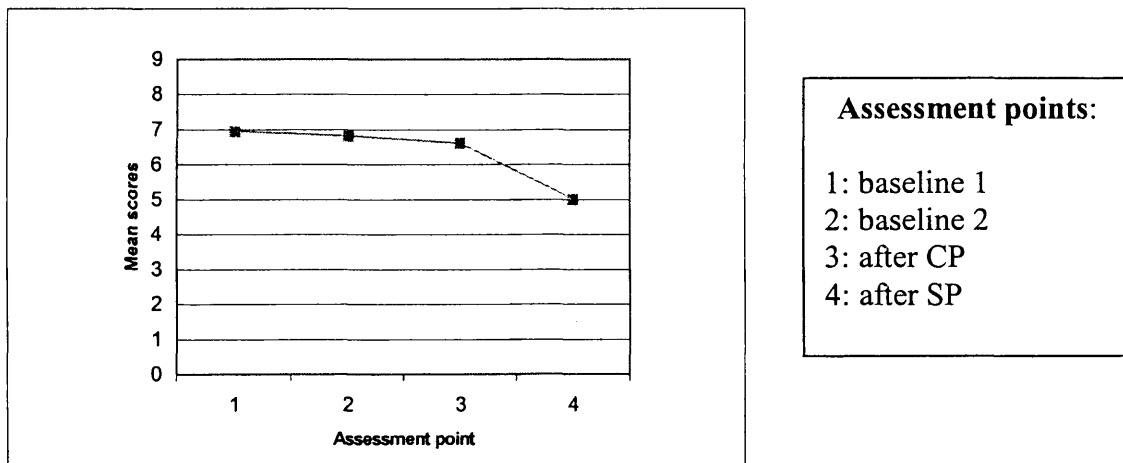
Table 1.12: Mean PQRST scores from a total of 44 statements rated by five participants in TO2 at each assessment point

Assessment point	Mean score	Standard deviation
1 (baseline 1)	6.94	2.78
2 (baseline 2)	6.81	2.64
3 (after CP)	6.61	2.81
4 (after SP)	5.00	2.03

Table 1.13: Wilcoxon tests showing comparisons of scores for total of 44 statements rated by five participants in TO2 at different assessment points (statistically significant improvements in bold)

	Wilcoxon tests comparing scores at assessment points :					
	1-2 (baseline 1- baseline 2)	1-3 (baseline 1-after CP)	1-4 (baseline 1-after SP)	2-3 (baseline 2-after CP)	2-4 (baseline 2-after SP)	3-4 (after CP- after SP)
Z	-.342	-.458	-3.687	-.044	-3.568	-3.447
Sig	p=.732	p=.647	p=.001	p=.965	p=.001	p=.001

Figure 1.2: Mean PQRST scores for participants in TO2 at different assessment points



Discussion of results and analysis from a group perspective

By combining scores from each individual's PQRST statements into a single data set each for TO1 and TO2, a crude analysis of the psychosocial outcome of the SP and CP was provided. Before discussing the results, it should be stressed that this approach to analysis meant that all details of individuals were lost. This included the different number of issues which each participant included in their assessment, the relative intensity of their feelings, and the degree to which different issues changed or not during the course of the programmes. The analysis also concealed the nature of each person's psychosocial issues and the language used to describe them. In terms of change, it is impossible to know whether this is based on dramatic change on statements rated by a few participants, for example, or on minor changes in all statements. Given the process of data preparation for analysis from a group perspective, then, findings

should be treated with caution. However, several issues arising from this analysis are now discussed.

A double-baseline assessment was carried out with partners in TO2. PQRST scores remained stable within this time period, indicating that change at future points could be attributed to the intervention rather than participants' own attempts to adjust to their problems. This finding also suggests that the participants' familiarity with the assessment through repeated administration of the PQRST (or with the author) did not result in change, a finding endorsed by Nichols et al (1996). It is of course only possible to speculate that the same finding would have occurred in the partners in TO1 had they received double-baseline assessments.

In order to evaluate the maintenance effects of the programmes, participants in TO1 were assessed immediately after all intervention had ceased and again eight weeks later. Results showed no significant change in PQRST scores at the final assessment compared with that carried out immediately post-intervention. This could be taken to indicate that the significant positive changes noted after the SP programme were maintained not only through the CP but at least two months beyond the end of intervention. This is a different finding to that of Nichols et al (1996), who noted no improvement in relatives' PQRST scores immediately after attending family therapy intervention, but significant improvements three months after intervention had ceased. Nichols et al felt that their results were consistent with the suggestion that family therapy aimed to give insight, but that this may need time to create change. Comparisons between Nichols et al's and this study's results should be treated with caution, as the intervention methods were fundamentally different. However, from this analysis it could be suggested that the approach taken in the SP promoted immediate and maintained positive change in psychosocial state rather than delayed change that may be effected by family intervention.

The main aim of Study One was to assess the effects of the SP and CP on the psychosocial state of the participants. It was hypothesised that the SP would result in improved psychosocial state, as measured by issues reported for the PQRST. This has been supported by the group results of both TO1 and TO2, which showed significant reduction in severity of issues immediately post-SP, a finding which backs up Rice et al's (1987) conclusions (see Chapter 2.5.2). The CP did not appear to affect the severity

of psychosocial issues: scores for both sets of participants remained virtually static post-CP compared with the assessment carried out previously. Because of the links between conversation, relationships and psychosocial well-being, it was considered possible that the CP, by providing strategies to enhance partnerships' communication, might also enhance partners' psychosocial state. The results from a group perspective show this not to be the case, although the results from TO1 suggest that the CP was able to maintain the positive effects brought about during the SP.

Despite the limitations of analysing the quantitative data from a group perspective, already described in relation to both this study and those of Rice et al and Nichols et al, the results provide limited insight into the psychosocial effects of the SP and CP. They have enabled limited comparisons with the group results reported in previous studies. They also provide context for the following analysis of data from an individual perspective, which, in turn, will be used to re-examine those arrived at by the method just described.

3.4.2 PQRST results from an individual perspective

In an attempt to determine the effects of intervention on individuals' psychosocial state (ie as related to issues included on the PQRST), the scores of each participant's separate statements at every assessment point were compared and subjected to a Friedman test. Because SPSS was used for statistical analysis, and because of the low numbers in the analysis, significance level was set at 0.05, and significance levels reported are exact probability. Suggestions for setting a more stringent level (Leach, 1979) are, however, acknowledged. Data sets in which overall significant change was found were subjected to Wilcoxon signed-rank tests.

Participants in TO1

Friedman test results for individuals in TO1, displayed in Table 1.14, showed no significant change across the period of the CWC project for participants 1, 2 and 3, (Judith, Fatima and Lauren). Significant change was noted for participants 4, 5 and 6 (Tina, Kurt and Carole). Wilcoxon signed-rank tests were used on their data in an attempt to ascertain at which point in the programmes change occurred. The results of this individual analysis are found in Table 1.15 and explored further below. Figure 1.3 summarises participants' mean scores at each assessment point.

Table 1.14: Mean PQRST scores at each assessment point and Friedman tests for each participant in TO1 (statistically significant changes in bold)

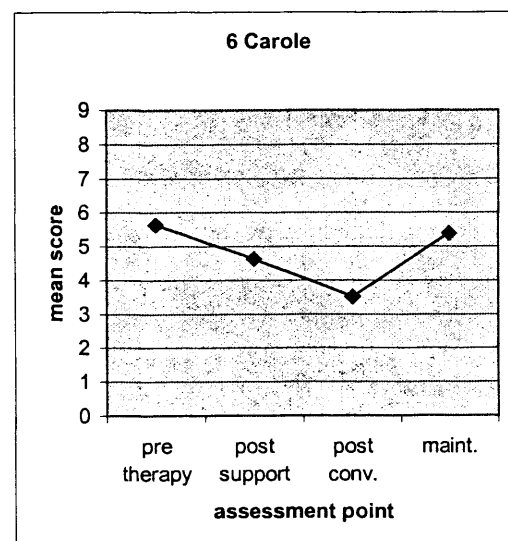
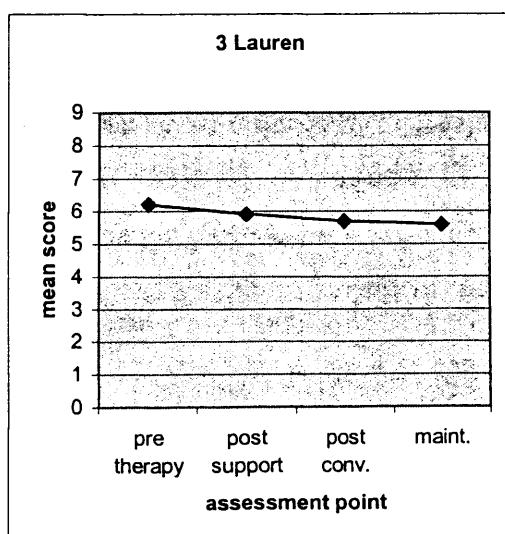
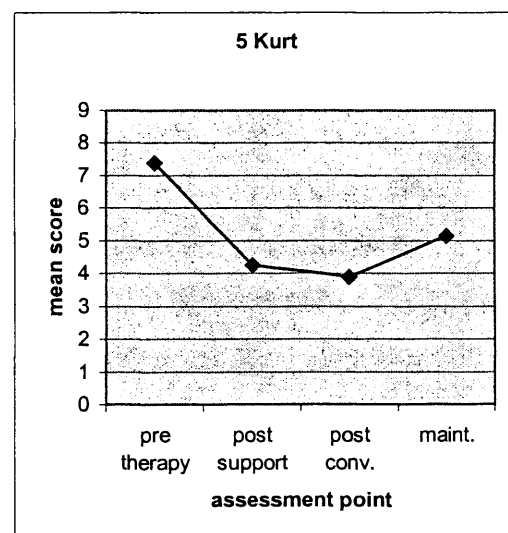
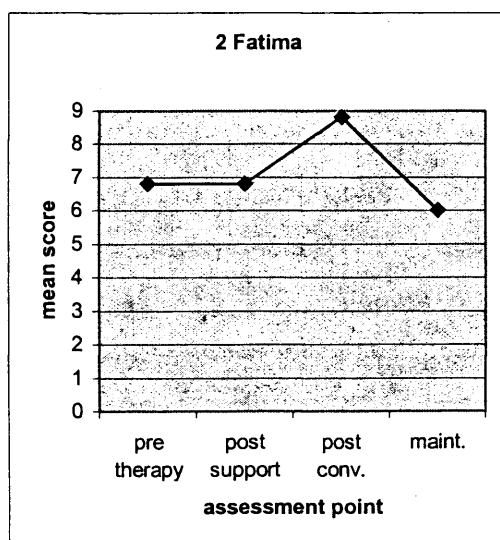
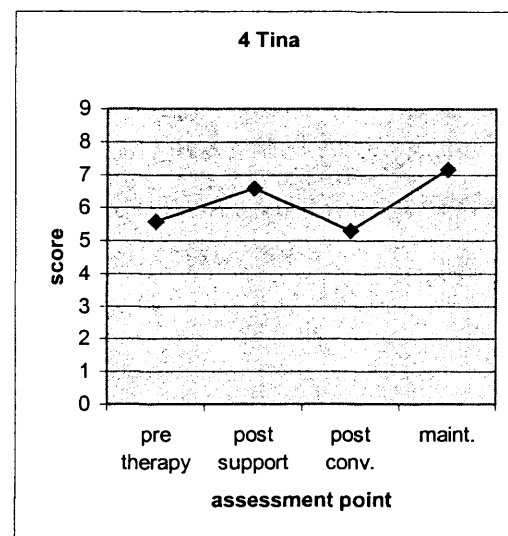
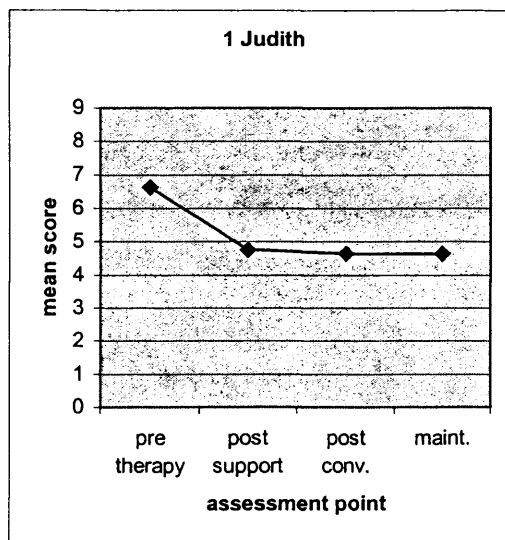
Participant	*No. of statements	Mean score at assessment point:				Friedman test		
		1 baseline (SD)	2 after SP (SD)	3 after CP (SD)	4 maintenance (SD)	Chi-square	DF	Sig
1 Judith	8	6.63 (1.77)	4.75 (1.58)	4.63 (2.39)	4.63 (0.52)	6.838	3	p=.077
2 Fatima	5	6.80 (2.39)	6.80 (1.79)	8.80 (0.45)	6.00 (3.00)	5.093	3	p=.165
3 Lauren	10	6.20 (0.79)	5.90 (2.23)	5.60 (1.83)	5.83 (1.07)	1.988	3	p=.575
4 Tina	7	5.57 (1.72)	6.57 (1.13)	5.29 (0.76)	7.14 (1.86)	9.984	3	p=.019
5 Kurt	8	7.38 (1.85)	4.25 (1.58)	3.88 (1.25)	5.13 (0.99)	14.540	3	p=.002
6 Carole	8	5.63 (1.19)	4.63 (1.30)	3.5 (0.76)	5.38 (0.52)	13.746	3	p=.003

* Only one participant from TO1 and one from TO2 chose to include the maximum of ten statements on the PQRST. This was inevitable given the nature of the assessment, but it is acknowledged that this influenced the data analysis method.

*Table 1.15: Wilcoxon tests showing comparisons of scores at different assessment points for each participant in TO1 who showed overall change across the project (statistically significant changes in bold; those marked * show a deterioration in scores rather than improvement)*

Participant	Wilcoxon tests comparing scores at assessment points:					
	1-2 (baseline -after SP)	1-3 (baseline- after CP)	1-4 (baseline-after maintenance)	2-3 (after SP- after CP)	2-4 (after SP-after maintenance)	3-4 (after CP-after maintenance)
4 Tina	-1.823	-.541	-1.980	-2.264	-.740	-2.041
	p=.068	p=.589	p=.048*	p=.024	p=.459	p=.041*
5 Kurt	-2.200	-2.388	-2.388	-1.006	-.962	-2.271
	p=.028	p=.017	p=.017	p=.314	p=.336	p=.023*
6 Carole	-1.298	-2.388	-.707	-1.807	-1.236	-2.549
	p=.194	p=.017	p=.480	p=.071	p=.216	p=.011*

Figure 1.3: Comparison of mean scores for each participant in TO1 at each assessment point. Significant change across the project was noted for participants 4, 5 and 6



An attempt is now made to explore individual patterns of change for partners in TO1. It was possible to separate individual's qualitative statements provided for the PQRST into those relating to conversation or communication and those related to other psychosocial issues. This was done for each person in an attempt to link changes to the CP or SP. The full sets of PQRST statements for each participant are found in Appendix 1D. Other assessments from the CWC project are considered where appropriate. Participants for whom significant change in PQRST scores occurred are considered first.

- **Tina (participant 4)**

It can be seen on Tables 1.14 and 1.15 that changes in Tina's PQRST scores were statistically significant, though marginally so, over the period of the study. There was no significant improvement in scores after the SP, in fact they slightly increased at this stage. They significantly decreased again after the CP, although to a level only marginally lower than they were at baseline. Because of this pattern, it is not possible to tell whether the CP was effective in reducing scores or merely acted to level the imbalance that occurred after the SP. Scores significantly increased at the final assessment after the eight-week maintenance period and also between the initial and final assessment. This could indicate that the withdrawal of intervention resulted in a deterioration of Tina's psychosocial issues, to levels, which were worse than they were at the start of the study. All of these findings differ from those of the group analysis.

Tina's PQRST statements were concerned with psychosocial issues other than communication, such as social isolation and lack of freedom and support. Given the nature of her statements it could be hypothesised that any positive change in scores would occur after the SP, when the types of issues she raised in the PQRST were explored. This was not the case. Change after the CP cannot be attributed to improved conversation patterns between Tina and her husband, as CA revealed no change. Changes in her other assessments (see Table 1.9) also give no clues to her pattern of change.

- **Kurt (participant 5)**

Kurt's PQRST scores significantly decreased after his participation in the SP, indicating that it had a positive effect on issues rated, and this improvement was maintained after the CP. These scores reflect those of the group analysis. What differs, however, are his

scores from the final assessment, eight weeks after intervention had ceased. At this point his scores significantly deteriorated, although not to pre-intervention levels.

Most of Kurt's statements were related to his difficulty adjusting to changes in household roles, relationship difficulties with his wife, social isolation and lack of professional support. Discussion of these issues formed part of the content of the SP, so it is possible that this resulted in improvement in Kurt's scores at that point. It can also be noted that Kurt felt more knowledgeable about stroke issues, and perceived improved functional communication of his partner after the SP, which may have affected his results.

- **Carole (participant 6)**

Carole's scores began to decrease after the SP, but change only reached significance after the CP. This could be taken to indicate a steady improvement in her psychosocial issues during intervention. Her scores significantly worsened again at the final assessment point, reverting to almost pre-programme level. None of Carole's results reflect those found in the group analysis.

Like Tina, none of Carole's statements reflected communication-related issues covered in the CP. Instead, they largely related to restrictions on social and work life and about the degree of dependency, which her husband had on her. The PQRST data therefore does not clearly relate to the improvements she made after the CP. One possible account for this is that discussion of her psychosocial issues during the SP was the beginning of change which was not fully realised until later in the CP (which would be a similar finding to that of Nichols et al, 1996). Improvement in scores after the CP also cannot be attributed to change in her and her husband's conversation patterns, as CA revealed no change. Changes in her other assessments provide no particular insights, other than that she felt significantly more knowledgeable about stroke issues after both the SP and CP.

Analysis of the data from an individual perspective revealed no significant change in PQRST scores for three participants in TO1. Their data therefore do not reflect the results from a group perspective. These are now briefly discussed.

- **Judith (participant 1)**

Although no *significant* change in PQRST scores over the course of intervention was noted, scores did decrease from a mean of 6.63 at baseline to 4.75 after the SP. After that, they remained stable. This could indicate a possible positive influence of the SP. Judith was the only participant in TO1 whose CA revealed changed patterns in her and her husband's conversation after the CP. She also showed improvements on the POSI Scale and CETI, and her husband's assessments suggested he felt less disabled in talking and understanding by the end of the study. However, none of these positive changes were reflected in statistical improvement in Judith's PQRST scores. Her statements related to her fears about her husband having another stroke, disappointment at reduced socialising, and frustrations about communication. All of these issues were covered at some point in the intervention. It is not possible to tell from the PQRST data why Judith showed no significant psychosocial change.

- **Fatima (participant 2)**

Fatima's scores showed no significant change across the study. This may have been a result of the low number of statements included in the statistical analysis, so her results should be treated with caution. It can be seen that Fatima's scores did deteriorate after the CP, before levelling out again after the maintenance period. The PQRST data and analysis cannot shed light on Fatima's movement in scores at this stage, as her statements were related to her worry about her husband's health and her nervousness at coping with new responsibilities. It should be noted that English was Fatima's second language, and that this did seem to have an impact upon her completion of the assessment. While completing the PQRST at each point, Fatima asked for clarification of the different meanings of some adjectives, her confusion over which led to discrepancies in her ratings. With discussion and re-rating, these were overcome. It may also be possible that Fatima's problems with understanding English may have meant that she did not fully understand the concepts being covered in the CP, and resulted in increased (albeit non-significant) PQRST scores at that time, though every effort was made during sessions to ensure she understood. The available data cannot confirm any of these possibilities.

- **Lauren (participant 3)**

Lauren's ten PQRST statements conveyed her concerns about a variety of issues, including a loss of closeness with and support from her husband, negative feelings about

how people treated him, the effects of his stroke on her own health, and a lack of support from healthcare professionals. Her mean scores remained virtually the same throughout the study, which could suggest that none of Lauren's psychosocial issues were addressed. Positive changes by the end of the project in her perception of her knowledge of stroke issues and her husband's functional communication, and his feeling less disabled in talking and understanding, as reported on assessments (see Table 1.9), were not manifest in a change in PQRST score for Lauren. It is not possible to tell from the available data why this is so.

Participants in TO2

The data for people participating in TO2 were analysed from the same individual perspective as those for people in TO1. The data from participant 10, who completed the first three assessments but not the final one, were included in this analysis. Friedman tests (summarised in Table 1.16) showed no significant change in scores across the period of the project for participants 10, 11 and 12 (Gwen, Jenny and Denise), but a significant change for participants 7, 8 and 9 (Ursula, Amy and Vera). The data for the latter three women were therefore subjected to a Wilcoxon signed-Rank test, in an attempt to ascertain at which point in the programme change occurred. The results of these tests are found in Table 1.17. Figure 1.4 summarises participants' mean scores at each assessment point.

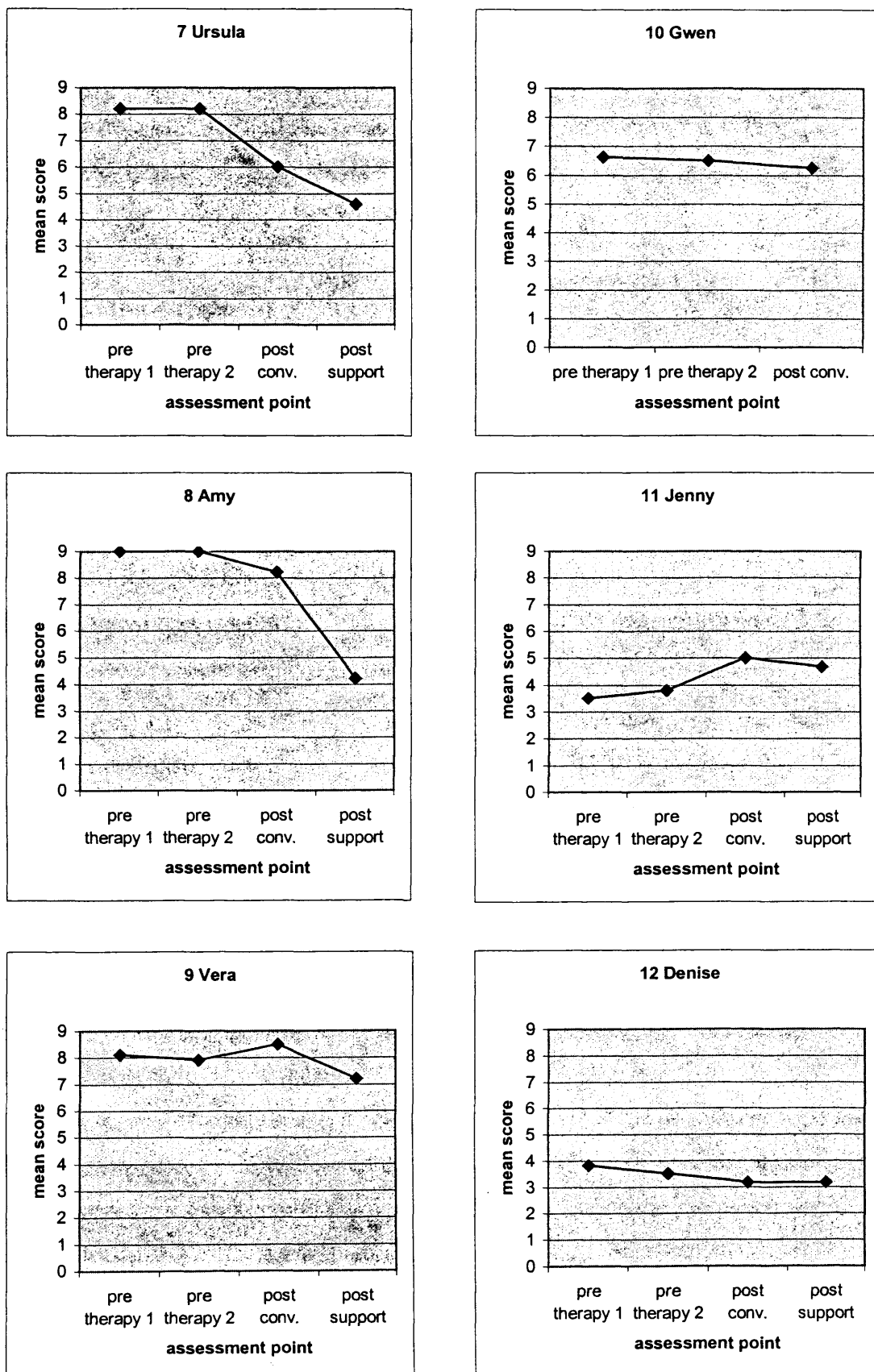
Table 1.16: Mean PQRST scores at each assessment point and Friedman tests for each participant in TO2 (statistically significant changes in bold)

Participant	No. of statements	Mean score at assessment point:				Friedman test		
		1 b'line 1 (SD)	2 b'line 2 (SD)	3 after CP (SD)	4 after SP (SD)	Chi-square	DF	Sig
7 Ursula	5	8.80 (0.45)	8.20 (1.30)	6.00 (3.24)	4.60 (0.89)	10.953	3	p=.012
8 Amy	9	9.00 (0.00)	9.00 (0.00)	8.22 (2.33)	4.22 (1.56)	24.429	3	p=.001
9 Vera	10	8.10 (1.20)	7.90 (1.20)	8.50 (1.27)	7.20 (0.79)	9.908	3	p=.019
10 Gwen	8	6.63 (2.33)	6.50 (2.14)	6.25 (3.54)	---	0.667	2	p=.717
11 Jenny	6	3.50 (2.74)	3.83 (2.64)	5.00 (2.37)	4.67 (2.80)	6.081	3	p=.108
12 Denise	6	3.83 (2.04)	3.50 (1.05)	3.17 (0.41)	3.17 (0.41)	0.538	3	p=.910

Table 1.17: Wilcoxon tests showing comparisons of scores at different assessment points for each participant in TO2 who showed overall change across the project (statistically significant improvements in bold)

Participant	Wilcoxon tests comparing scores at assessment points :					
	1-2 (baseline 1- baseline 2)	1-3 (baseline 1-after CP)	1-4 (baseline 1-after SP)	2-3 (baseline 2-after CP)	2-4 (baseline 2-after SP)	3-4 (after CP- after SP)
7 Ursula	-.816	-1.604	-2.060	-1.841	-2.070	-1.134
	p=.414	p=.109	p=.039	p=.066	p=.038	p=.257
8 Amy	.000	-1.000	-2.680	-1.000	-2.680	-2.536
	p=1.000	p=.317	p=.007	p=.317	p=.007	p=.011
9 Vera	-.408	-.680	-2.165	-1.511	-1.552	-2.131
	p=.683	p=.496	p=.030	p=.131	p=.121	p=.033

Figure 1.4: Comparison of mean scores for each participant in TO2 at each assessment point. Significant change across the project was noted for participants 7, 8 and 9



Analysis of individual data sets of participants in TO2 revealed that all scores remained stable between the first and second baseline assessment. This mirrors the result from a group perspective, and again could be taken to suggest that any changes noted thereafter could be attributed to their participation in the programmes. The individual patterns of psychosocial change of partners in TO2 (as related to PQRST scores) are explored below, along with the nature of their PQRST statements and other CWC project assessments. Participants for whom significant change in scores occurred are considered first.

- **Ursula (participant 7)**

Ursula's PQRST scores began to decrease after the CP, but change did not reach significance until after the SP. All of Ursula's statements related to her worries about her own and other people's difficulties in communicating with her husband, issues, which were discussed in the CP. It is therefore possible that Ursula had begun to feel more positive about these issues as a result of the programme, and that these were either addressed for her further in the SP or required time to produce significant change. Changes noted through CA in Ursula and her husband's conversation patterns after the CP may also be a factor in these positive results.

- **Amy (participant 8)**

Amy's PQRST scores remained stable until after the SP, when they decreased significantly, mirroring the group perspective results. All of Amy's statements were related to psychosocial issues other than communication. They were predominantly about her sadness and frustration at her and her husband's reduced social life, loss of activities and plans for retirement. They also included negative feelings about their friends' inability to cope with her husband's difficulties, and about extra responsibilities that Amy was shouldering at home. It should therefore be possible to link Amy's reduction in scores to these issues being addressed in the SP, but it can be seen on Table 1.8 that Amy actually only attended the first session of the SP. It seems unlikely that this introductory session could create such a dramatic change in her psychosocial state as rated by the PQRST. There is nothing in the available data that can account for this.

- **Vera (participant 9)**

Vera was the third and final participant in TO2 to show significant overall change in PQRST scores. Like Amy, Vera's scores showed no significant reduction until after the

SP, thus mirroring the findings of the group analysis. All of Vera's statements were related to psychosocial issues other than communication. These included negative feelings related to giving up a course she was doing before her husband's stroke, lack of time, opportunity and money to take part in social activities alone, lack of help around the house from her husband, and seeing less of her family. Unlike Amy, Vera attended all but one of the SP sessions. It is possible that her improved psychosocial state, as rated on the PQRST, can be attributed to the SP having addressed the issues recorded. Vera also showed positive change on the POSI and CETI over the course of the project.

Individual results for the remaining three participants in TO2 revealed no significant change across the project, and these therefore do not reflect those obtained from the group perspective. These are now briefly discussed.

- **Gwen (participant 10)**

Gwen completed the CP and three assessment points before leaving the project, throughout which her PQRST scores remained virtually the same. Gwen's statements related to difficulties communicating with her husband as well as worry and sadness about loss of joint activities, concerns at dealing with finances, and embarrassment at relying on others for transport. Results suggest that the CP had not created change in these issues. Gwen stated that she left the programme because of personal and interpersonal issues. These may have had an effect on her PQRST results. It is not possible to use the available data to examine these issues.

- **Jenny (participant 11)**

Jenny's PQRST statements related to both communication and general psychosocial issues. These included missing conversation with her father with aphasia, and fear about him not being able to communicate if something was wrong. She reported anger and disappointment at lack of hospital support, monotony of the daily routine, and guilt at not giving attention to her children while with her father. Jenny's PQRST scores did not change significantly as a result of the study, even though she and her father showed positive change on other assessments. Possible reasons for no change may be the small numbers in the statistical analysis (six statements), or the low severity level of Jenny's scores. Like her sister Denise's, they appear to be lower initially than those of the spouses in the study. This may affirm the research that suggests that relatives who do not live with or who are not married to the PWA suffer less psychosocially than spouses

do (Cantor, 1983). Jenny's scores may indicate that her psychosocial state was sufficiently strong before the programme and therefore had little room for improvement. Alternatively, the programmes may have failed to address her issues. The available data is unable to shed light on these possibilities.

- **Denise (participant 12)**

Denise's PQRST statements were related to her restrictions on her freedom, her tiredness resulting from caring for her father, guilt at not taking him out more, worry about his health and safety and a dread of the effects on her family if something were to happen to him. Like her sister Jenny, these issues, which were rated with low scores throughout, were not significantly affected by the programmes, despite change in other assessments. Again, this may be a result of the small numbers in her analysis. The available data cannot account for Denise's findings.

3.4.3 Effect of time post-stroke on results

Partners' individual PQRST results were viewed in relation to the length of time since the PWA's stroke in an attempt to judge any effects of this on score change. As can be seen on Table 1.18, no strong pattern was evident. Some partners who had been living with and/or caring for their PWA for under two years (ie Ursula, Amy and Vera) showed improvement in scores, and may therefore be considered to have benefited from the intervention, while others did not (ie Fatima, Gwen, Jenny and Denise). Some partners for whom aphasia had been part of their lives in the relative long-term - ie from around three to five years - did not show improvements in psychosocial state as measured by reduction in PQRST scores (ie Tina, Judith and Lauren). A small number, however, did (ie Kurt and Carole). This finding may indicate that partners can benefit from intervention several years after stroke and that services should continue to be offered in the longer term. However, these suggestions should again be treated with caution given the limitations of the PQRST data.

Table 1.18: The effects of time post-stroke on significant improvement in PQRST scores

Overall significant improvement in PQRST scores		No overall significant improvement in PQRST scores	
Partner	No. of years/months since onset of relative's aphasia	Partner	No. of years/months since onset of relative's aphasia
Kurt	4.0	Tina*	4.9
Carole	2.11	Judith	4.0
Ursula	1.6	Fatima	0.8
Amy	1.0	Lauren	4.2
Vera	1.2	Gwen	1.7
		Jenny	1.4
		Denise	1.4

* Tina did show significant improvement in scores after the CP but overall her scores were significantly worse at the end of the study than they were at the start. She is therefore classified as making no overall improvement.

3.4.4 Comparison of results from group and individual perspectives

The PQRST data was analysed from an individual perspective. The aims of this were to enable comparison with the results from the group analysis and also to overcome some of the limitations of group analysis previously recognised, ie to provide fuller data about the effects of the programmes on individuals. These analyses are now compared and discussed.

As can be seen in Table 1.19, the results from the individual analysis do not fully reflect those from the group analysis.

Table 1.19: Implications of analysis of PQRST scores from group and individual perspectives (change refers to statistically significant change)

TO1		
Assessment point	Implications of analysis from group perspective	Implications of analysis from individual perspective
Across the project	significant improvement in psychosocial state* across the group	significant change in psychosocial state* for three participants: deterioration for participant 4; improvement for participants 5 & 6
After SP (compared with baseline)	improvement in psychosocial state across the group	4: no change 5: improvement 6: no change
After CP (compared with SP)	no change (effects of SP therefore maintained)	4: improvement 5: no change 6: improvement (compared with baseline assessment)
After maintenance period (compared with CP)	no change (effects of SP therefore maintained)	4: deteriorated 5: deteriorated 6: deteriorated
TO2		
Across the project	significant improvement in psychosocial state across the group	significant improvement in psychosocial state for three participants (7,8,9)
After baseline 2 (compared with baseline 1)	no change	7: no change 8: no change 9: no change
After CP (compared with baseline 2)	no change	7: no change 8: no change 9: no change
After SP (compared with CP)	improvement in psychosocial state across the group	7: improvement (compared with baseline assessment) 8: improvement 9: improvement

**as indicated by significant change in PQRST scores*

This table shows that when analysed from a group perspective, data from participants in TO1 implied improvement in psychosocial state (as indicated by positive change in PQRST scores) to have occurred across the group after the SP, with no significant change after the CP or maintenance period. From an individual perspective results look very different. These suggest that only three people who took part in TO1 showed any significant change in PQRST scores. Two of these did not in fact change after the SP, but after the CP. All of their scores significantly worsened between the end of the programme and the maintenance period, although the scores for two of these were significantly lower at this time than at the start of the study.

Analysis of data from a group perspective for people receiving TO2 indicated no change in scores between baseline assessments, no change after the CP, but significant improvement after the SP. This could be taken to indicate that the SP had had a positive effect on psychosocial state. The results of analysis from an individual perspective, however, show change to have occurred in only three out of the six participants. Each of their scores showed no significant change between baselines or after the CP, but significant improvement by the end of the SP. The findings from the individuals in TO2 therefore reflect more closely those from the group analysis.

The differing results achieved from the two methods, with those from the individual perspective being more conservative, force a reconsideration of those from the cruder group analysis. The group analysis suggested that the SP had resulted in improved psychosocial state across the board, that the CP had had no effect, that psychosocial change was as a result of the programme and was maintained up to eight weeks after the programmes had ceased. The results of the individual analyses challenge these suggestions. They indicated that the intervention produced significant score change in only half of all participants, with the SP having a positive effect on four people, the CP having a positive effect on two, and the programme appearing to have resulted in negative overall change for one person. Although the evidence for no change between baselines remains in the individual analysis, that for maintenance of the benefits after intervention had ceased does not.

It is proposed that the findings from the latter analysis are more meaningful, as they are based on individual score sets rather than on an average across all participants.

However, it should be noted that the individual analysis itself is limited by the method

of data reduction required – albeit less extreme than that for the group perspective - in order to carry out statistics. For example it is still not possible to see how individual statement scores may have changed over the course of the programmes or contributed to the overall results. This should be borne in mind for the following discussion.

3.5 Discussion

This study aimed to evaluate the effects of the SP and CP on the psychosocial state of the participants, and to assess the value of the PQRST for research and clinical use. The conclusions that can be drawn about the programmes' ability to bring about psychosocial change, ie as assessed on the PQRST and analysed from the more appropriate individual perspective, and about the PQRST as an outcome measure, are now discussed.

3.5.1 The psychosocial effects of the Support and Conversation Programmes

Results suggest that changes identified are due to the programmes

Because no change in scores was found between baseline results, later changes are unlikely to be due to repeated administration of the assessment, familiarity with the tester (also see Nichols et al, 1996), or to the partners' independent attempts to adjust to their problems. However, as only a small number of people were assessed over two baselines, and as one person showed positive change after the SP despite attending only one session, this conclusion should be treated with caution.

The SP created positive change for some but not all participants

It was hypothesised that the SP, which specifically addressed psychosocial issues, would result in significant positive psychosocial change, as assessed by the PQRST. Because only four participants (Kurt from TO1 and Ursula, Amy and Vera from TO2) showed reduced scores after the SP, the hypothesis is only partly supported.

The statements of each participant were broadly examined in an attempt to explore any links between the issues raised and whether or not change occurred. The statements of three (Kurt, Amy and Vera) who showed significant improvement in scores after the SP, related to psychosocial issues rather than communication, so it could be suggested that

these were addressed sufficiently in the SP to create change. A closer look at Amy's results, however, clouds the picture. Amy attended only one of the SP sessions, making the link between the programme and her psychosocial improvement extremely tenuous and suggesting that other factors may have been responsible. However, what those factors are could not be uncovered with any of the available data. Ursula's statements could not be used to account for her positive psychosocial change after the SP, as these were all related to communication. Possible reasons for her pattern of change are discussed in the following section.

The remaining participants showed no significant improvement in scores as a result of the SP. Some, such as Judith and Carole in TO1 did show some non-significant improvement. The rest showed almost stable scores throughout the study. The content of their PQRST statements reflected different combinations of issues about psychosocial and communication factors affecting their lives. The results from other assessments carried out for the CWC Project also showed a range of positive changes at different assessment points. The data in this study could not therefore be used to uncover why these people did not appear to benefit from the SP, or why some people did experience significantly positive change.

The CP created positive change for a small number of partners

Although the focus of the CP was not to explore psychosocial issues *per se*, it aimed to provide strategies for more effective conversation between partnerships. Because of the links between conversation, relationships and psychosocial well-being, it was suggested that the CP might also result in positive psychosocial change. The CP did bring about improved PQRST scores for two participants (Tina and Carole from TO1). However, this does not appear to be linked to more effective conversation patterns, as the CA revealed no change (though it is acknowledged that the CA may have failed to pick up any change). Their statements revealed no insight to the change: none were about communication, rather they described concerns about caring for their husbands and the effect this had on their own personal lives and freedom. Tina's also described lack of support. One possibility is that such issues were addressed for Tina and Carole within the CP. Another possibility for Tina's improved PQRST scores after the CP is that at that stage they merely returned to pre-SP levels (after which they slightly increased, reasons for which are not clear from the data). Carole's scores began to improve after the SP, and finally reached significance after the CP. It is possible therefore, that Carole's

change at this stage was a delayed impact of the SP (a similar finding to Nichols et al, 1996) or, indeed, a combination of the effects of both programmes.

The PQRST was clearly unable to account for the positive changes for Tina and Carole after the CP, nor, conversely, for why some participants who appeared to show improved conversation patterns after the programme showed no psychosocial change. For example, CA suggested that both Judith (from TO1) and Ursula (from TO2) showed changed conversation patterns after the CP. Other assessments suggested they also felt more knowledgeable about stroke and aphasia. However, Judith's PQRST scores showed no significant change throughout the study. Ursula's begun to improve after the CP but only reached significance after the SP. Ursula's statements were all linked to her own and others' communication difficulties with her husband. Perhaps these had begun to be addressed in the CP.

It appears, then, that the CP was able to create change in PQRST scores for some people. What remains unclear from this study is why and how change did or did not occur, and whether or not improved psychosocial wellbeing, as rated by the PQRST, is related to changed conversation patterns or to some other factor/s not evident within the available data.

Positive change was not long-lasting

Significant deterioration in PQRST scores of TO1's Tina, Kurt and Carole after intervention had ceased for eight weeks, suggests that change resulting from the programmes was short-lasting for them. Each showed a different pattern of change. Despite showing a deterioration of scores after the maintenance period compared with the final post-intervention assessment, Kurt's scores remained significantly lower at the end of the study than they were at the beginning, indicating an overall positive effect. Carole's scores also significantly deteriorated after the maintenance period compared with the post-intervention assessment, but her final mean score reverted to a level, which was almost the same as that at the beginning of the study. Tina's scores, on the other hand, were significantly worse at the end of the study than they were at the start. This could be taken to indicate that withdrawal of intervention might be detrimental, though the small data set implies these findings should be treated with caution. However, they may be valuable clinically in alerting therapists to a range of possible

reactions to the cessation of intervention and to a need to consider how to withdraw services in a way which enables any positive benefits of a programme to remain.

3.5.2 The research and clinical usefulness of the PQRST

The PQRST scores were analysed from a group perspective, the precedence for which had been set by previous studies. Looking at results from this analysis alone, one could claim the existence of tidy evidence for the SP's ability to create positive, relatively long-lasting psychosocial change, but none for the CP. However, delving a little deeper by analysing each person's data individually highlighted a more complex picture, in which the effects of both programmes are less clear. The latter findings imply that those from the group perspective do not fully represent what happened for participants and create a false picture of the effects of the programmes. Results are achieved from such reduction of the data that logically it is not clear what they are saying. This is also likely to apply to Rice et al and Nichols et al's studies, which used similar broad group analysis: one is left wondering what is concealed in the data and questioning claims for success of their respective interventions. It can be concluded that group statistical analysis of PQRST data used in this and previous studies is too broad and limited to be useful.

By highlighting individual patterns of change across the study, the individual analysis provided some detail about change for participants at different time points that was not possible to achieve in the group analysis. However, preparation of the data for statistics still entailed losing sight of the relative contribution of each statement to the results, and whether and how each was resolved. Analysis from an individual perspective did facilitate exploration of additional factors that may have influenced results - a requirement that had been identified from previous research but prior to this study had not been undertaken (Rice et al, 1987) - such as time living with aphasia, attendance at the sessions, the nature of participants' psychosocial issues as reported in their statements, and additional outcomes of the programmes. This exploration suggested that factors outside of the intervention might have contributed to change. However, the method used in this study was unable to capture what those might have been.

Aside from the difficulties analysing PQRST data statistically encountered in this and previous studies, a range of other issues suggest its use in research and clinical settings is limited. The first relates to the restructuring of people's statements during interview

into ones that can be rated with an adjective. Rice et al and Nichols et al needed to reframe data to a considerable extent in order to come up with statements that were common between participants, or turn contributions by PWA into rateable statements. In this study, restructuring statements was done jointly with the participants, using their own terms, to ensure they reflected as accurately as possible their meaning and language. This process was very difficult for one person for whom English was her second language. She also required support to understand the subtle differences between certain adjectives used in rating the statements, which resulted in erroneous scores that required verifying. This was very time consuming for what is supposed to be a rapid assessment measure. Nichols et al commented on the relatively simple and repetitive use of language in the PQRST and the preference for ratings based on words rather than numbers. However, several participants in this study commented on the concentration needed over a fairly long period in order to retain a sense of the different meanings and to complete the assessment. This suggests that the PQRST may be particularly unsuitable for people who do not have a sound grasp of language, or who tire and lose concentration easily. This may include PWA (with whom Nichols et al used it) or people with cognitive communication difficulties.

Nichols et al liked the idiographic nature of the PQRST, which allowed people to choose their own issues to be rated, and this was a driver in the decision to use it for the CWC Project. Compared with the pre-determined structure imposed by standardised measures, this does seem to be a particular strength of the assessment. The interview process through which the issues were reached provided a good opportunity for building rapport and shared knowledge before intervention began. The issues were probably not used to inform intervention optimally in the present study because the broad content of the programme was set in advance for purposes of control. This may have been a factor in lack of change, ie intervention did not sufficiently address issues raised (Nichols et al, 1996). The seriousness and apparent 'depth' of some of the issues mentioned (see Appendix 1D) suggest this as a distinct possibility. However, because the issues as they were noted for the PQRST lack any contextual information, it is not possible to determine whether this was the case. It may also be possible that issues deemed important to participants at the first assessment were not actually the ones which were important at follow up. Certain issues may have been resolved through intervention, or replaced by new, more prominent ones (a suggestion made by Herrmann, 1997). Because of the nature of the assessment and its use in the CWC project, this concern

was not addressed. In the clinical setting, introducing new statements onto the PQRST at different times during blocks of intervention should not be problematic, and may ensure that intervention continues to target issues which are meaningful to the client. This may be more difficult in a research setting, when issues are generally set at the beginning of a study as a baseline for measurement of change over time or types of intervention. However, it should be possible to build an allowance for the introduction of new issues into research design. Given its other limitations, it is doubtful whether the PQRST is the most suitable means of recording and monitoring them in the first place.

Both Rice et al and Nichols et al felt that the PQRST provided a lot of fascinating qualitative data, though only Nichols et al featured qualitative data in their study report. The present study attempted to make more use of the qualitative data by attempting to link the content of individuals' statements to patterns of change. However, because the statements were provided with no contextual information, this exercise provided only clues about whether or how the SP and CP may have influenced psychosocial change, and said nothing about whether this represented first or second order change (Nichols et al, 1996), as discussed in Chapter 2.5.2. It was not possible to explore the relative importance of the statements to individuals, what lay behind them or how they interacted. Obviously the data available was unable to provide any clues as to how each person coped with the effects they described. The exercise did however highlight a range of psychosocial difficulties experienced by the partners in the study and their feelings about them, and therefore makes some contribution to the existing body of knowledge about the different psychosocial effects of stroke and aphasia for partners.

3.6 Study Conclusions

In summary, this study attempted to evaluate the effects of a group support programme and a group conversation programme on the psychosocial state of partners of PWA, using the PQRST. Results from individual analysis of the quantitative data could be taken to suggest that both programmes had a positive effect on the psychosocial issues reported by some participants. They therefore contribute to the small body of literature that describes and provides evidence for therapeutic procedures for managing psychosocial difficulties of partners. However, because the measure used required extensive reduction of individual data to enable statistical analysis, this conclusion must

be treated with caution. Exploration of the data alongside other measures began to suggest that factors outside of intervention might also have influenced participants' psychosocial outcome. The PQRST and data it provided was obviously unable to capture these, but this study suggests that it is clearly important to untangle how and the degree to which such factors affect outcome. To reiterate Nichols et al's (1996, p770) point: '... knowledge of outcome is of little value without an understanding of the reasons for change.' In relation to this, while facilitating the programme sessions I noted that factors related to the organisation and content of the programmes and interactions within the groups also appeared to be influencing participation. I recognised then that these might also therefore influence outcome, but that we had failed to address this issue within the methodology or measures chosen at the inception of the CWC Project. It became obvious that in order to provide a more complete evaluation of the programmes, we needed to access the partners' own perspectives on the factors that had influenced their participation in the sessions, their own perceptions of psychosocial outcome and of how any change came about. So, like much research, the present study and the CWC project from which it emerged produced no definitive answers about the effects of the programmes, but created a new question, which is:

From the participants' perspectives, what factors within the content and process of the SP and CP, and outside of intervention, influenced programme participation and psychosocial outcome?

Study Two of this thesis attempts to answer this question.

It is suggested that the range of limitations already discussed renders the PQRST less than optimal as a tool for objective or subjective assessment of psychosocial state, in both research or clinical use. Measures further along the quantitative continuum are likely to provide more objective, statistically amenable evidence of change and be time-efficient, if that is what is called for, though their limitations are already well-reported (see Chapter 2.5.1). The PQRST does provide data about individuals' personal psychosocial issues, but not what lies behind those issues, how each issue is affected by intervention, or the process by which they are or are not resolved. Without knowing those things, it is not possible to know what the PQRST is actually measuring and whether indeed it is our interventions for partners that are influencing psychosocial state, or something else. An approach that provides more contextual and therefore more

meaningful insider-perspective information is required. An exploration of this is the focus of the following chapter and remaining studies.

CHAPTER 4

INSIDER PERSPECTIVES AND THE QUALITATIVE PARADIGM

Introduction

This chapter explores the evolution of the thesis in terms of its shift towards accessing insider perspectives and the adoption of a qualitative paradigm. This shift was necessitated by the issues and new research question emerging from Study One and through my own evolution as clinician and researcher. The chapter discusses the importance of insider perspectives on the psychosocial effects of aphasia for partners, and for programme outcome and process evaluation. It provides a rationale for accessing them through qualitative rather than quantitative methodology, in particular through the use of in-depth interviews, and reviews the most pertinent recent qualitative studies. The chapter concludes with a discussion of trustworthiness in qualitative research.

4.1 Researcher perspectives: the quantitative paradigm

It was evident from the literature review in Chapter 2 that the majority of research to date about the psychosocial effects of stroke and aphasia for both PWA and partners, and about intervention evaluations, has been carried out from the ‘researcher’s perspective’. In this predominant and long-standing perspective, research findings reflect the questions and methods set by the researcher. It usually sits within the positivist paradigm, in that it is based upon a realist ontology, ie the view that ‘reality’ exists and can be fully and objectively apprehended, free of bias. It usually adopts quantitative, deductive methods and analysis, with a focus on measurement of groups of subjects and statistical description and inference (Blaikie, 1993).

Chapter 2.5 described criticisms of the use of quantitative-based questionnaires for studying psychosocial effects and intervention outcomes. The first study of this thesis attempted to address some of those criticisms by using an idiographic measure that aimed to capture ‘insider perspectives’ by enabling participants of a Support and Conversation Programme to define their own psychosocial issues for assessment. The study proved that this was insider perspective with a small I and P: the nature of the PQRST meant it was only able to provide broad clues to psychosocial effects on and change for individuals, and no insight into how change may or may not have occurred. Its use therefore resulted in an incomplete understanding of psychosocial outcome, and

incomplete evaluation of the programmes. To more fully understand insider perspectives, a shift to a qualitative paradigm was required. This is now described.

4.2 *Insider perspectives: the qualitative paradigm*

Research from an insider perspective places importance on understanding the subjective experience of the individual and the meanings that inform their behaviours (Murphy et al, 1998). Understanding experience does not fit within a traditional positivist paradigm and its analysis methods, with its emphasis on reductionism, but within a constructivist paradigm. In this there is relativist ontology, which assumes multiple realities which are sometimes conflicting and which may change as re-constructions and understandings shift. There is therefore often a reluctance to impose *a priori* theoretical frameworks at the outset of research. Its epistemological position is that knowledge is created by both the researcher and the researched.

Insider perspectives are often accessed using qualitative, inductive research methods and procedures. According to Denzin and Lincoln (1994), qualitative research gets much closer than quantitative research to the perspectives of the person studied. Qualitative methodology has developed in recent years from a wide range of disciplines, including anthropology, social sciences, psychology and education. From these, several ‘traditions of enquiry’ have emerged, including for example ethnography, grounded theory, phenomenology, symbolic interactionism and narrative approaches (Creswell, 1988). There are now many trusted texts that illuminate the qualitative paradigm, the various traditions of enquiry, the ontological and epistemological positions therein, and related research methods. This section therefore summarises the major themes pertinent to this thesis and the reader is referred to referenced texts for additional information.

Mason (1996) outlined the principal components of qualitative research. First, it is grounded in a philosophical position that is broadly concerned with how the social world is interpreted, understood, experienced or produced. In contrast, quantitative approaches are considered more removed from the natural social context. Qualitative research is based on methods of data generation and analysis that are flexible and sensitive to the real-life, natural social context in which the data is generated (eg through observation, diary methods or interviews). These are able to produce ‘thick’ or ‘rich’, ie complex and

conceptually dense, detailed data (Denzin, 1994; Hammersley, 1996). Methods of analysis attempt to understand and explain this complexity and detail. Again, this is in contrast to quantitative approaches in which data is often collected in a standardised, structured format with analysis focused on charting correlations and relationships between variables. The qualitative paradigm emphasises holism. By its nature it is inductive, hence theory-generating (Patton, 1990; Banister, Burman, Parker, Taylor and Tindall, 1994) and process oriented (Denzin, 1994). The evolution of the thesis to this point and beyond can be described as process-oriented.

The epistemological position of the remaining studies of this thesis emphasises the meaningful world of the people involved in the research. It recognises that each person's interpretation of what is occurring is the reality of the situation for her or him and that no two people react in the same way to an event or situation, for example, living with a PWA or attending an intervention programme. Individual characteristics, such as those described in Chapter 2.4.8, are considered to influence perception and reaction. Again, this perspective is in contrast with other theoretical perspectives which take a more impersonal, objective approach to data collection.

One way of representing evidence of an individual's interpretation of a situation is through examining the person's verbal accounts of experiences, personal attitudes, beliefs and perceptions. Semi-structured or in-depth interviews have found to be particularly effective for this, and is the approach perhaps most extensively written about in the literature on qualitative methods. May (1993) identified four types of interviews ranging from structured to unstructured, where 'semi-structured' is defined as having specified questions, but enough openness to allow flexible probing that goes beyond the interview schedule. This type is referred to as an interview guide approach (Patton, 1990), which lies somewhere in the middle in terms of its results along the dimensions of flexibility, comprehensiveness, and comparability of responses, or systematic organisation of the data. Semi-structured interviews are the instrument and data gathering procedure of choice for several qualitative analytical methods, including Framework Method (Ritchie and Spencer, 1994) and Interpretative Phenomenological Analysis (IPA) (Smith, 1996), which feature in Study Two (S2) and Study Three (S3) respectively of this thesis. Interviews have been used to collect data in many studies of personal experience, in most qualitative studies of the psychosocial state of PWA and

their partners, and in qualitative programme evaluations (eg Brocklehurst et al, 1981; Le Dorze and Brassard, 1995; Pound et al, 2001).

4.2.1 Insider perspectives on psychosocial change for PWA and their partners

Anderson (1992) noted a serious gap in knowledge of coping with stroke from the perspectives of stroke survivors and their carers, rather than from that of medical and other service providers and researchers, despite the fact that:

‘A sound, effective and ethical approach to stroke must lie in awareness of and attention to the experiences, values, priorities and expectations of patients and their carers – they are the people who live with the consequences of the illness and who shoulder its burdens’ (p217).

Over a decade later, and insider perspective research related to PWA and particularly their partners, is still relatively rare. Ellis-Hill (2001) noted Vrabec’s (1997) finding that only 6% of studies of caregiver support and burden took the perspective of the individual within the caregiving situation. However, there is now a small body of insider perspective, qualitative literature from which to draw. Though the findings of those studies that preceded the CWC project and data collection for this thesis were summarised in Chapters 2.3 and 2.4, their methods are now considered in more detail to provide some contextual understanding of the methods chosen for the rest of the thesis.

Anderson’s (1992) primarily quantitative longitudinal study of 173 stroke survivors and their supporters living in London did include an insider perspective, qualitative component. He carried out structured interviews during which respondents completed a variety of self rating scales and questionnaires adapted from published assessments, relating to housework and social activities, subjective health and stress, stigma, interaction, irritation and mood. He illustrated his statistical results with verbatim comments made by the respondents during the interviews, but did not describe any method of data collection or analysis. Despite this, his study appeared to be one of the first attempts to describe life changes after aphasia by incorporating the respondents’ own words and language.

Le Dorze and Brassard (1995) carried out semi-structured interviews with nine people with aphasia (mixed types and ranging from two- to 14-years post-onset) and a relative

or friend of each. The interviews were focused on the themes of work, personal relationships and difficult communicative situations, and findings were framed within the World Health Organisation's (1980) conceptualisation of handicap. In their literature review Le Dorze and Brassard noted a lack of systematic analysis in previous related work (such as that by Lebrun, 1978). They provided a brief description of their own data analysis method, which entailed transcribing the interviews then labelling, classifying and grouping the data, following grounded theory procedures described by Strauss and Corbin (1990). They mention that 'the interviewer attempted to be presuppositionless' (p242) and their focus on description of the data with minimal interpretation imply that their findings were grounded in the participants' reports. They did not mention the position or impact of the researchers on the analysis process (Henwood and Pidgeon, 1992), which is one aspect of 'reflexivity' and trustworthiness in qualitative data (Henwood and Pidgeon, 1992; Miles and Huberman, 1994; Elliott, Fischer and Rennie, 1999). This issue is considered in greater depth below.

Parr et al's (1997) study was the first large insider-perspective, qualitative study to report about the psychosocial effects of aphasia for 50 PWA, within a social model framework, though partners were not the focus of their work. The ensuing book provided a brief outline of their methodology. In-depth interviews were used to allow important topics and issues to be raised by the respondents in addition to those broached by the researchers' topic guide, and to enable exploration of issues in the terms and language of the people taking part. Data analysis followed the 'Framework Method' (Ritchie and Spencer, 1994), designed for use in social policy research. This entailed classifying and indexing the verbatim interview data and organising it onto charts or matrices displaying individual responses, themes and issues. These provided an indication of the range and pattern of views on each issue. Parr et al (1997) provided no critical discussion of their methodology. Bell's (1998) review of it, however, praised the interweaving of direct interviewee quotations with the researcher's constructed narrative, which gave an overall impression of the centrality of the interviewees' experiences. But Bell also implied that, by 'placing themselves and their 'research' questions and concerns right at the back of the stage which they have constructed with their participants' (p179), the authors' obvious yet implicit role in the research partnership, and in constructing and presenting the findings, was obscured from view. Despite that, the chosen method for Parr et al's study enabled the authors to identify a

range of environmental, structural, attitudinal and informational barriers contributing to peoples' experiences of aphasia and changes in their psychosocial lives.

As this thesis was nearing completion Hunt and Smith (2004) published their IPA of interviews with four carers (two spouses, two daughters) about their experiences since their partners' stroke six months or less post-onset. The IPA method enabled them to identify three common themes in the data: uncertainty about the consequences of stroke, personal physical and emotional impact, and strength of relationships with their partner and with the stroke rehabilitation ward. Hunt and Smith provided verbatim extracts to illustrate individuals' experiences within those themes. Their approach therefore provided an idiographic exploration of experience and the uniqueness of each individual, as well as similarities with other participants. The process of IPA is described fully in Chapter 6.

4.2.2 Insider perspectives on partner programme outcome and process

Insider perspectives on programme evaluation have also been called for. It has been suggested that successful programme evaluation requires recognition of the interests of all 'stakeholders', including members of the groups affected by programmes and evaluative conclusions about them, as well as those who make decisions about the future of the programme (Murphy et al, 1998). Recent initiatives within health and social services research emphasise the importance of accessing user views and requirements, and promoting user participation in the planning and evaluation of services (Coulter, 1997; Department of Health, 1999, Wheeler and Grice, 2000). A related issue arising from Study One was the need to uncover different factors that might have influenced partners' participation in the programmes and psychosocial change. For evaluation to be complete, therefore, outcome needed to be distinguished from process. This requirement has been articulated in some existing partner intervention studies, though the difficulties of defining and measuring process have been recognised (Rice et al, 1987; Nichols et al, 1996; Pound et al, 2001). Murphy et al (1998, p223) have usefully distinguished outcome evaluation from process evaluation. The first can be considered to assess the effects produced by programmes. The second aims to illuminate and understand the internal dynamics and organisation of a programme and investigate informal patterns and unexpected consequences, as well as

formal activities and anticipated outcomes. In other words, process evaluations focus on how something happens or works, rather than the results obtained.

Programme evaluation and process characterisation require detailed familiarity with all aspects of a programme, in particular a sensitivity to unanticipated events (Murphy et al, 1998). Qualitative methods are suited to this, and are therefore useful for developing explanations of the events and processes that lead to specific outcomes, and in yielding theories and explanations of how and why processes and outcomes occur (Murphy et al, 1998). That is, qualitative methods are well suited to studies concerned with understanding events and behaviour, holistically, in the context in which they occur in everyday life, and to understanding the process by which such events and behaviours come about. Because they acknowledge the multiple experiences of participants, they enable individual experiences and views to be heard and therefore to contribute to the implementation of policies (Murphy et al, 1998).

Shadish (1995) considered the introduction of qualitative methods to be a 'milestone accomplishment' for programme evaluation. They have now been applied to programme evaluations in the fields of community health and family medicine (Reinharz, 1994; Beattie, 1995). Within aphasiology, there has been a recent call for and growth of interest in the use of qualitative approaches for evaluating services for partners of PWA (Long, 1994; Cant, 1999; Le Dorze, Crouteau, Brassard and Michallet 1999; Simmons-Mackie and Damico, 1999; Wells, 1999). However, at the time of the CWC project and the inception of work for this thesis, there were but a handful of published qualitative evaluation studies (eg Bowling, 1977; Borenstein et al, 1987), none of which had attempted to systematically uncover insider perspectives on process of change. Since then, however, Pound et al (2001) have described their use of analysis of interview comments from four wives of PWA to both develop and evaluate the impact of a skill-training and information-giving course. Their study and its methods are now reviewed as the issues it raised provide context for and situate Study Two, which follows this chapter.

Pound et al (2001) carried out in-depth interviews, following a topic guide, with four women whose husbands had aphasia, as a means of eliciting autobiographical descriptions of their lives before and since their husband's stroke. These were used to create content for a support course and as a means for delivering it. Evaluation of the

course was via interviews immediately and six months after the course, in which questions and probes were used to elicit participants' evaluations. The interviews were analysed for recurring themes by an independent researcher using the Framework Method, a method already well utilised for uncovering user perspectives and programme evaluation (Ritchie and Spencer, 1994). This involved creating a matrix that allowed participants' views and responses on various themes to be tracked individually and compared, and cross-checked by the course leader. Pound et al (p481) suggested that such a process was 'in keeping with procedures used in interpretative and narrative analysis, both of which acknowledge variability of interpretation and ways the same information can be represented in research results' (Riessman, 1993).

Pound et al suggested that the autobiographical reports provided a naturally occurring means of understanding the complex nature of peoples' experiences and revealed the necessarily partial impact of the course, and how the course and other factors impacted on the lives of the participants. They suggested that they allowed an honest, authentic and realistic appraisal of the success and failures of the intervention, and therefore created authentic, consumer-relevant outcomes. Indeed, their paper provided a detailed exposition of the impact of aphasia on the partners' lives and how their support programme was developed. Of particular interest here is the method of evaluating the course. This included a content comparison of themes between interviews and an analysis of answers to direct questions about the course. They also used, before and after the course, the HADS (Zigmond and Snaith, 1983), a quantitative self-administered rating scale of anxiety and depression. No significant changes in HADS scores suggested that there were no measurable changes in participants' emotional state as a result of the course. However, the qualitative data revealed that three participants perceived the course as having had positive effects. Reasons behind these perceptions included that the course had enabled them to reflect on their roles and personal situations, to feel affirmed and valued, and to consider new ways of managing problems and communication breakdown. In response to direct questions about the course, all participants described it in positive terms, and suggested that the nature and delivery of the course, including aspects related to the personality and approach of the facilitators and the course setting and environment were influential in this. It is not known whether this positiveness was a reflection of the interviewer's questioning, the participants' acquiescence, or perceived actual positive change. This is because the researchers' did not describe their own position or contributions, an issue which will be returned to in

Chapter 4.3. The qualitative data also revealed reasons behind why the fourth participant had not felt the course to be useful (she did not need the support and felt her husband was easy in comparison with the others), and factors related to partners' continuously changing life circumstances which affected progress and change. These included disruptions related to deterioration in their husbands' health and problems ancillary to aphasia, including coping with their husbands' behaviour, unhappy pre-stroke relationships, managing family demands and time, and dealing with their own uncertainty, despair, fear and exhaustion.

Pound et al's stated aim was to 'evaluate the short- and longer-term impact of the course' (p480). Their findings, summarised above, suggest that their qualitative method of data collection and analysis achieved this aim, and more. It exposed changes that had not been identifiable on the quantitative HADS, various factors related to course content and process, and factors related to individuals' circumstances that affected participation and change. This confirms the qualitative paradigm's suitability to the research question of Study Two.

To conclude, Murphy et al (1998) pointed out that the goal of all evaluation research should be to establish knowledge about which we can be reasonably confident, and to provide findings that are relevant to policy makers and practitioners. Therefore decisions about whether quantitative or qualitative methods (or a combination of both) are most appropriate to a particular research problem should be made on the basis of which approach is likely to answer the question most effectively and efficiently. They suggested that the choice should rest on the degree of knowledge of the phenomenon to be studied: 'the more that is known about a programme and its underlying theories, the more possible and logical it becomes to use experimental design. The less that is known, the more it makes sense simply to try to understand the basic components' (p221). It is obvious from Study One that 'less' rather than 'more' is known about whether and how the SP and CP affected the psychosocial state of their participants: this is one reason why the qualitative paradigm has a role herein. It will enable an exploration of both the outcome and process of programme participation and change, from the perspectives of the participants, and thereby provide a more complete evaluation of the Support and Conversation Programmes featured in Study One. This should therefore provide an evaluation which is meaningful to the participants and for any future development of the interventions.

4.3 Rising to the challenges of qualitative methodology and ensuring trustworthiness

The shortcomings of qualitative methodology are well documented (eg Taylor and Bogdan, 1984; Neuman, 1997). They are summarised below, and the reader is pointed to Murphy et al (1998) for a comprehensive criticism of both qualitative and quantitative methods.

Qualitative methodology is often seen as ‘less scientific’ than quantitative, for example because of the inability to replicate studies or generalise from them (Murphy et al, 1998). Some suggest that these criticisms may be overcome if enough description is available in qualitative research to allow some application of results to other settings (Leedy, 1997).

A potential problem with qualitative evaluations is questionable assumptions about participants’ willingness to participate in them and their comfort about revealing, and later use of, their personal problems and opinions (Murphy et al, 1998; Pound et al 2001).

In terms of data collection, this has been criticised for being unstructured and unwieldy (Murphy et al, 1998). Pound et al (2001) recognised that gathering and analysing data was time- and labour-intensive, and that to use such an approach in a clinical setting would require clinician training in interviewing and data analysis. This has implications for staffing and costs (Judge and Solomon, 1993; Damico et al, 1999; Pound et al, 2001), which would not be the case for quantitative measures such as surveys or questionnaires. Pound et al (2001) also suggested that using themes from qualitative data to evaluate practice may not be acceptable to some insurance providers, administrators or clinicians who regard RCTs as the only acceptable means of assessing clinical outcomes (see for example, Pring, 1999; Servaes et al, 1999; Tompkins et al, 1999).

Perhaps the greatest challenge of qualitative research is ensuring and proving the ‘trustworthiness’ of its findings. This important issue is now considered in some depth, in an effort to determine appropriate standards for the studies which follow, and against which the studies can be judged. ‘Trustworthiness’ in qualitative research has been related to that of ‘validity’ in quantitative research, though the term and processes of judging ‘validity’ is considered inappropriate for the qualitative paradigm, because of

its source in quantitative epistemology (Banister et al, 1994). In qualitative research, terms such as 'credibility' (Eisner, 1991), 'verification' (Creswell, 1998), and 'understanding' (Wolcott, 1994) are used. Each of these implies, in one way or another, that a study seems to make sense, is authentic and that it can be trusted (Denzin, 1994).

The use of 'trustworthiness' as an evaluative standard has now become such a widely shared principle in qualitative research (Creswell, 1998) that it has yielded endlessly different versions or 'canons' of trustworthiness (Tesch, 1990), more than can be reviewed here. Because evaluation criteria should vary according to the study's epistemological location (Denzin, 1994; Willig 2001), the criteria described below reflect the epistemological position of the remainder of this thesis. They draw particularly on the writings of Henwood and Pidgeon (1992), Miles and Huberman (1994), Smith (1996), Elliott et al (1999) and Yardley (2000).

4.3.1 Researcher bias / reflexivity

Researcher bias, ie the degree to which the researcher influences findings, is a common criticism of qualitative research. Many authors, including some within the field of aphasiology, have suggested that it must be eliminated from the analysis process in order for results to be honest (eg Damico et al, 1999). In the literature just reviewed, it was suggested that some researchers have not considered – or at least have not acknowledged or demonstrated – the influences that their own backgrounds and position may have had on their findings (Le Dorze and Brassard, 1995; Parr et al, 1997; Pound et al, 2001). It has been argued, however, that the researchers' own assumptions and perspective inevitably shape the research process (Bell, 1998; Willig, 2001). What is required, therefore, is 'reflexivity', also known as 'owning one's perspective' (Elliott et al, 1999) or 'checking for researcher effects' (Miles and Huberman, 1994). This is an aspect of trustworthiness for qualitative research featuring interpretation of data. Self-reflection is considered to make data more 'authentic' and thus trustworthy, because the biases and positions underlying or lurking behind interpretations are made clear (Henwood and Pidgeon, 1992; Smith, 1994; Willig, 2001). In Studies Two and Three of this thesis I will acknowledge and reflect on myself as a researcher and clinician, and provide evidence of the influences that I or the research methods had upon participants' experiences, disclosures, and my interpretations of them.

A second form of reflexivity is participant reflexivity. Smith (1996, p195) noted that 'the reflexive focus can be upon the participant, the investigator, or both', which raises the question of the degree to which the participant is able to be a 'self-reflexive agent'. Miles and Huberman (1994) suggested that 'better' data arises from more 'articulate and reflective informants'. It has been suggested that engaging participants as co-researchers or co-analysts is a cornerstone of reflexive, phenomenological practice (Smith, 1994). It therefore makes sense for 'researchers who make use of co-operative inquiry [to] capitalize upon the participants' propensity towards reflection and reflexivity, and [to] enlist interested parties as co-researchers in a research project' (Smith, 1996, p196). Study 2 describes an innovative method of carrying out such co-operative inquiry.

4.3.2 Sensitivity to context

Yardley's criteria of 'sensitivity to context', conceptualised in relation to the construct of trustworthiness, is about showing a credible and hence trustworthy relationship between various facets of the study and contexts in which it takes place. This can take many forms (Smith and Osborn, 2003). For example, sensitivity to the theoretical context in which the study is situated is demonstrated in this thesis through the literature review. Sensitivity to the data relates to Henwood and Pidgeon's (1992) 'importance of fit' between analytic categories and data, in that analytic categories generated by the researcher should fit the data well. This echoes Elliott's (1999) criterion of grounding analysis in examples, which is a way of demonstrating the sensitivity of the analytic ideas to the data that generated them. In S2 and S3, analytic categories are sensitive to the data in so far as they are introduced, explained, and supported throughout by verbatim data extracts. Grounding ideas in the data is also crucial to the Framework Method and IPA, the methods of analysis for S2 and S3 respectively, and is a factor in transparency, another factor of trustworthiness (Yardley, 2000), considered below.

4.3.3 Commitment, rigour, transparency and coherence

These four criteria can be considered to demonstrate the substantive evidence for trustworthiness.

Commitment

Yardley (2000) defines commitment as the degree to which the researcher engages, or has engaged over time, with the research domain (the problem, the population, the method, etc.). Commitment resulting in greater engagement and thus understanding of

the research issue may be considered a factor in trustworthiness. Here I would argue that my engagement for eight years, as both clinician and researcher, with the psychosocial experiences of partners and PWA, and interventions for them, indicates a degree of engagement.

Rigour

Yardley's 'rigour' is defined by Smith and Osborn (2003, p233) as the 'thoroughness of study in terms of the appropriateness of the sample to the question in hand and the completeness of the analysis undertaken'. Rigour creates trustworthiness by demonstrating that the study method is adequate to the research question: this issue as pertinent to S2 and S3 is discussed separately within the studies themselves.

Rigour is also associated with checking analytic ideas at various points along their evolution, for example with outside colleagues or researchers. This increases trustworthiness by showing that independent views, or spot-checks of analysis 'agree with it or, at least, do not contradict it' (Miles and Huberman, 1994, p267). Another way of expressing this idea is Elliott et al's (1999) 'providing credibility checks'. Again, the processes undertaken to ensure rigour in S2 and S3 are described fully within the studies.

Transparency

Transparency relates to the degree to which the research process is clearly outlined throughout the study, in the form of a 'paper trail' which can be independently audited (Huberman and Miles, 1994; Smith, 1996). A study in which analytic decisions are clearly documented as well as grounded in examples of the data will be more trustworthy (Henwood and Pidgeon, 1992; Elliott et al, 1999). As well as independent auditing, 'mini-audits' during the course of the study are recommended (Smith and Osborn, 2003). In S2 and S3 I describe and provide evidence of my attention to transparency through auditing.

Coherence

Coherence is the degree to which all the transparent, auditable material actually makes sense to, or resonates with, the reader (Elliott et al, 1999). Beyond the 'importance of fit' between analytic categories and data, mentioned earlier in relation to sensitivity, coherence is also linked to the integration of theory (Henwood and Pidgeon, 1992; Elliott et al, 1999). That is, 'relationships between units of analysis should be clearly

explicated and their integration at different levels of generality should be readily apparent' (Willig, 2001). This bears particular relevance for S3, which takes a thematic analysis to the point of theorising. My endeavour at providing coherence therein comprises conducting the best analysis and the most coherent write-up possible. The reader must judge the coherence of this.

4.3.4 Impact and importance

This principle - perhaps more about usefulness than trustworthiness - is the degree to which the study is important in the sense that it has, or potentially will have, an impact on some area of practice and/or theory (Yardley, 2000). This relates to the concepts of 'transferability', 'fittingness' 'utilization' or 'application' (Henwood and Pidgeon, 1992; Miles and Huberman, 1994), to which can be added Elliott et al's (1999) criterion of the degree to which the research fulfils its general or specific goals. The impact and importance of the studies, which follow, will be discussed therein.

4.4 *Ethical issues*

Ethics are particularly important in qualitative research (Mason, 1996), with certain risks of harm differing from those within quantitative research (Beauchamp, Faden, Wallace and Walters, 1982 in Murphy et al, 1998). These might include anxiety, stress, guilt and damage to self-esteem during or after in-depth interviewing, or publication of data. However, as Tschudin (2000) noted, ethics is a broad topic. She suggested that part of a clinician's ethical duty towards care-receivers is to provide holistic care, but that cannot be provided until we understand, for example, the care-receivers experiences of aphasia or of participating in intervention. Therefore it could be argued that learning about these is part of our ethical duty.

Suggestions for minimising risk to participants include the researcher reflecting upon the possible ethical implications of the proposed work prior to any study, minimising residual risks by such measures as anonymisation of the data, considering how any potentially negative consequences of publication of the study may be contained, and attending to the requirements of informed consent prior to and throughout the research (Murphy et al, 1998). All of the studies in this thesis received ethical permission. The ethical considerations for S2 and S3 are considered therein.

Summary

This chapter has demonstrated the need for a shift to a qualitative paradigm in order to access insider perspectives on the psychosocial effects of aphasia for partners and on programme outcome and process evaluation. It has introduced the role of qualitative methodology – particularly that of semi-structured interviewing and the Framework Method – in existing related research. This role is considered further in the following studies. Finally, the chapter described a range of strategies for ensuring trustworthiness, against which the remaining studies in this thesis can be judged.

CHAPTER 5

STUDY TWO

**Insider perspectives on the factors influencing
participation in partner interventions
and psychosocial change**

Introduction

This study uncovers and reports the perspectives of partners on the factors affecting their participation in, and effects of, the group Support Programme (SP) and Conversation Programme (CP) described in Study One. Chapter 1 situates this study within the thesis, though the section which follows describes more fully its sources, rationale and aims. This is followed by details of the data collection and analysis method chosen for the study, and presentation and discussion of its findings.

5.1 Background, rationale and aims of the study

This study arises from several sources which are linked, but which are separated here to reflect the process by which it came about. The primary source was the CWC project, which evaluated the SP and CP from a variety of researcher-prescribed perspectives. The CWC project was also the source for Study One of this thesis, which attempted to objectively evaluate the psychosocial outcome of the programmes for the participants. In that study, the idiographic yet quantitative measure and analysis used was unable to sufficiently capture change in psychosocial issues or what lay behind outcome. The overall findings of Study One were reached as a result of work for this thesis, and therefore *after* my initial realisation that the perspectives of the partners on the factors influencing group participation and psychosocial outcome needed to be uncovered. The origin of this realisation was actually the group sessions that I facilitated as research SLT on the CWC project. As the sessions for the first set of partners progressed I was struck by the richness of the interactions within the groups, the bonds and the tensions, sessions in which everything and everybody seemed to gel one week and be fraught with contradictions and difficulties the next. I listened to reasons why some people could not attend, and observed others attending 'against the odds'. These observations highlighted, in very real terms, the complexities of both living with a PWA and of group work. I felt it was vital to try to capture these complexities in order to make full sense of the CWC project's other, predominantly researcher-perspective findings. The early group sessions also coincided with the developing drive within health and social services to evaluate services from the perspective of service users (Coulter, 1997; Department of Health, 1997). I felt bound to respond to this at a professional/clinical level. Also, given my involvement with and observations of the partners with whom I was working, I became personally interested in exploring their own perceptions of

factors affecting their participation in and change through the programmes, and of the programmes' usefulness for them. At that time, as pointed out earlier, no published studies of SLT intervention for partners of PWA had attempted to systematically uncover the processes behind outcomes: another rationale for this study. **The main aim of Study Two, therefore, is to understand partners' perspectives on the factors that influenced their participation in and change through the Support Programme and Conversation Programme.**

Coinciding with my decision to attempt to uncover partners' perspectives of the programmes was one of the participant's developing academic interest in the CWC project. 'Lauren', who took part in TO1b) (see Tables 1.1 and 1.2 in Study One for further details) was a university lecturer with experience of interviewing for research. She was also a qualified psychotherapeutic counsellor. As her participation in the programmes was coming to an end, Lauren offered to carry out post-programme interviews with the other participants, with the aim of discussing their perspectives of the programmes. Various factors led to the rationale for accepting her offer. First, as described in Chapter 4, the qualitative method of data collection through interviewing had been shown to be a particularly effective way of accessing insider perspectives. It had a history in uncovering the personal experiences of PWA and their partners and, though had not been used to evaluate intervention programmes for partners of PWA, had been used in other types of programme evaluation. Second, it was recognised that involving a research participant in the collection of evaluation data from fellow participants, ie as a co-researcher, though not usually possible, may constitute reflective and reflexive, co-operative enquiry (Smith, 1994; 1996: see Section 4.3.1). Lauren's experience as both a wife of a man with aphasia and as a group member meant she had first-hand experience of the issues likely to be discussed by the participants. The CWC project team felt that her experiences, knowledge and skills would be valuable in helping others to discuss their own experiences and views, and that she would offer empathy and support at a time when group participants may be mourning the ending of their group (Finlay, 1993). I, and Lauren, acknowledged that her own perspective on living with a PWA and on being part of the programmes, plus her own reactions to other members during sessions, may influence what she explored in the discussions, and what the participants chose to discuss or respond to. However I felt positive that Lauren's status as 'one of them' would encourage participants to be frank, open and honest in

their discussions and evaluation of the programmes. It is the data collected through Lauren's interviews that are the focus of Study Two.

This study utilises the Framework Method (FM) of data analysis (Ritchie and Spencer, 1994). The rationale for using this stemmed from its reported usefulness in uncovering insider perspectives of PWA and in programme evaluations, described in Chapter 4. When this study was conceptualised, FM had been used by Parr et al (1997) to successfully explore and report the experiences of 50 PWA (see Section 4.2.1 for review). Though these authors did not appear to attend to an important factor of trustworthiness - that of reflexivity - the method allowed them to ground their findings in the data and present the effects of aphasia on the PWAs' lives in a way which captured overall themes plus individual variations within them. In personal communication with Parr at the planning stages of this study, she suggested that the systematic nature of FM and its charting systems was suited to multiple data sets and provided a useful means of flexibly exploring emerging themes. With this in mind, and having compared FM with other methods of analysis, such as those used for grounded theory, it was felt that FM's structure would suit the requirements of Study Two. Since this study's inception, Pound et al (2001) have used FM in their design and evaluation of a partner programme (see Section 4.3.3). This illustrated that the method was able to uncover psychosocial needs and change for partners of PWA as well as factors related to programme content and individual circumstances that affected participation. However, the method needs further evaluation, with obvious attention to aspects of trustworthiness that has been lacking or not acknowledged in previous studies, if its potential as a SLT research and clinical tool is to be fully judged. **The second aim of Study Two, therefore, is to consider the appropriateness of the Framework Method for uncovering participants' perspectives on factors influencing participation in and change through the programmes featured in this study.**

5.2 Method: details and procedures

5.2.1 The researcher

It is acknowledged that I had the central role of devising and facilitating the SP and CP, in evaluating them and in analysing the interview data. Therefore my own perspective

on shaping the development of the research is acknowledged. It is hoped that the following information, which contributes to my attention to reflexivity or ‘checking for researcher effects’ (Miles and Huberman, 1994), will facilitate contextual understanding and subsequent reading of this study.

I do not have a spouse or relative with aphasia but as a SLT I have worked professionally with a variety of PWA and their partners. Rarely has this work been more intensive and intense than during the CWC Project, which involved me recruiting partnerships, and visiting them in their homes frequently and for lengthy periods of assessment, many of which were emotionally demanding for all involved. During group sessions my roles reflected elements of information-giver, educator, facilitator, counsellor, listener and fellow participant. Through these I learned much about the partners and their lives and developed a strong professional relationship with them. I did not always remain the objective, scientific, impartial research SLT, and attribute the inevitability of this to the nature of the work we were doing together. During this time I was supervised and supported by the first supervisor of this thesis and the larger group of academics and clinicians involved in the CWC project. Immediately after each session I made notes about issues arising in the group as a whole and for individuals.

It is acknowledged that my own desire for the programmes to be ‘a success’ for both participants and the research team could influence the findings I report. However, my professional, academic and ethical values have created a genuine interest in uncovering and reporting a balanced view of the effects of the programmes. Also, an ‘audit’ of my data analysis was built into the study to try to ensure a reflection of the content and meaning of the data that was as representative as possible of the participants’ own contributions. This auditing process is described in Section 5.2.5.

5.2.2 The interviewer

Lauren, a partner who had participated in TO1b), interviewed the remaining participants in her and the other groups. The rationale behind Lauren’s involvement and an introduction to the potential effects she would have on the research were provided in Section 5.1, and the latter are considered further in Section 5.3.

5.2.3 Participants and ethical considerations

The participants were all of the spouses or relatives of PWA who took part in the SP and CP, with the obvious exception of Lauren, who acted as interviewer. The programmes are described fully in Study One, in which Tables 1.1 and 1.2 provide summary details about the participants and the PWA.

At the penultimate group meeting the participants were invited to take part in the interviews. The aims of the interviews were explained and discussed, and written information sheets were provided. These detailed what would happen to the data once collected and issues of confidentiality (data would be transcribed and analysed for themes by me, with all references to people or places anonymised. Thereafter data may be seen by other members of the research team or used in research presentations or publications). To remove any sense of pressure to agree, participants were offered the opportunity to take time to think about whether they would like to be involved and give their decision over the telephone at a later date. They were offered a choice of venue for the interviews (own home or university department). All accepted the invitation to take part and chose their own home for the interview.

5.2.4 Data collection: interviews

Lauren conducted semi-structured interviews of between 50 and 80 minutes duration, between two and seven weeks after the final session or assessment period, and once the partners would have no more contact with the researcher. Lauren began the interviews with a reiteration of the aims and potential outcomes of the interview, and about her participation in the project. She stressed the importance of uncovering the interviewees' own experiences and perspectives on their involvement in the programmes, and of their opinions for shaping the development of future programmes and improving them where possible. She encouraged them throughout the interview to be honest in their feedback about the sessions. With (verbal and written) permission, the interviews were audio-recorded.

The interviewer worked from a topic guide devised by the researcher primarily to seek participants' views about the content and design of the programmes, factors that may have affected their participation in the sessions and their perception of change. The guide forms Appendix 2A. The interviewer was encouraged to explore issues introduced by the interviewees that were not necessarily featured on the guide. The number of

questions, the order in which they were presented and depth to which they were probed were therefore not standardised across the interviews. Lauren frequently referred to the programmes as 'the course'. For this reason both terms are used in the findings.

Immediately after some interviews Lauren made notes of her perceptions and interpretations of what had been discussed. She discussed these with me. It is acknowledged that these discussions may have influenced my data analysis and I therefore report in the findings occasions when Lauren's notes or interpretations were considered.

5.2.5 Data analysis

Interviews were transcribed. Organisation and analysis of the data followed the matrix-based approach of the Framework Method (Ritchie and Spencer, 1994). The analysis process followed six interconnected stages, described below.

Transcription

The researcher listened to each of the recordings before transcribing verbatim onto a word-processor document what both the interviewee and interviewer said. All references to names or places were changed. In order to allow examination of the interviewer's influences on the responses of the interviewees, transcriptions were finer than is usual for interview data. They included notation of phenomena such as overlap by the speakers, long pauses, occurrences of audible sighs and laughter, word emphasis, volume and speed. Turn and page numbers, columns for coding the data and for analytical comments were included on the transcripts. Appendixes 2B and 2C provide a transcript extract for one participant (Tina) and an explanation of transcription notation symbols respectively.

Familiarisation

Although I had not collected the interview data, familiarity with it was gained during transcription. In order to take fuller stock of the data and gain a feel for the material as a whole, the tapes were re-listened to and each transcript read and re-read. During this process, notes were kept about early ideas for analysis and a list was begun of key ideas, recurrent themes and issues that emerged as important to the interviewees themselves.

Identification of a thematic framework

From the list of themes and issues created during reading the transcripts, the labels of the key issues, concepts and themes were organised into a draft thematic framework, or index. The first audit process was introduced at this stage: the index was examined along with three transcripts by me and by an independent qualitative researcher with wide experience of using FM, who was acting as thesis advisor at the time. The advisor found the index to be rooted too heavily in the *a priori* research questions that had featured on the interview topic guide, and not grounded sufficiently in the interviewees' responses. A selection of transcripts were re-read and the index revised twice more with supervision by the advisor, before a working index which was responsive to the emergent and analytical themes was finalised. The index, which also features a numerical coding system, is featured in Appendix 2D.

Indexing

The thematic index was then systematically applied to the text of each transcript. This process involved making a decision about the meaning and significance of all passages of text and annotating them with one or more appropriate indexing codes. Because this process of making judgements is subjective and open to different interpretations, another auditing process was instated. This entailed both the thesis advisor and second supervisor, who also has wide experience of using qualitative research methods and analysing interview data, reading selected pages of two transcripts, together with their coding, in relation to the index. Both reported that the indexing was appropriate. The labelling/coding of the data allowed access to each reference within and between transcripts. This in turn enabled patterns, and the contexts in which they arose, to begin to be explored. Appendix 2E illustrates the indexing applied to Tina's transcript extract.

At the indexing stage an analysis was made of the nature and content of the interviewer's contributions and questioning style, and the degree to which these shaped participants' responses. For this, the interviewer's contributions in each transcript were read and summary notes made in the comments column about their impact.

Charting

Having applied the thematic framework to individual transcripts, four themed charts were devised. These enabled the data to be lifted from their original context and rearranged according to an appropriate thematic reference through a process of

summary, abstraction and synthesis. This enabled a picture of the data as a whole to be constructed and the range of individual experiences or views for each issue or theme to be explored further.

Both the *a priori* research questions and the thematic framework shaped the charts, with supervision by the thesis advisor. Five drafts of the charts were created before it was felt that they were capable of addressing the research questions while also capturing the essential essence of the themes that had emerged in the data. The charts covered perceptions of life before stroke and of the impact of stroke on psychosocial life and communication, and perceptions of the course and its impact. Each chart was created on a Word document. Chart subheadings were arranged in columns, with entries for each individual noted in rows beneath appropriate column headings. Three subheadings and three participants were included on each page of the document. The ordering of the individuals was the same on each chart, with participants in TO1 placed before those in TO2. Keeping cases in the same order and space on each page of the chart enabled the whole data set for each person to be reviewed easily once printed, and for systematic comparisons to be made within and between cases. The full headings and subheadings of each chart are shown in Appendix 2F.

Some of the chart headings were identical to index categories (eg 'work/education'). Others reflected themes, which emerged or were newly identified while indexing the data (eg 'anxieties and concerns before/during/after sessions'). Some categories from the index were omitted from the charts if they were minimally represented in the data or deemed insignificant (eg 'finance'). Others were subsumed into overarching chart headings (eg index headings 'verbal and written material/information', 'activities/exercises/role play' were subsumed under the chart heading 'evaluation of course content/information').

Each passage of coded text in the transcripts was re-read, studied, and a summary of what the interviewee had said was entered under an appropriate heading on the chart. An attempt was made to retain a sense of the interviewees' own language, and a system was employed to allow verbatim quotes and distilled summaries to be differentiated. The line number of the original text was always referenced on the chart so that the source could be traced and returned to for additional contextual information or re-

examination. This was designed to enable the process of abstraction to be examined during the audit process and to aid replicability.

Data for which the interviewer's contributions shaped participants' responses, which were influenced by my involvement in the assessment and therapy process or my post-interview discussions with Lauren were documented and differentiated on the charts.

Again, this was designed to make the analysis process transparent and examinable.

Appendix 2G provides an extract from Tina's chart, with its headings and entries, and a key to the charts. My summary and transfer of data from the indexed transcripts to the charts was audited and approved by the thesis's second supervisor, who examined the process for two participants.

Mapping and interpretation

Once the data had been charted according to the core themes, it was repeatedly reviewed and examined. During this process the original transcripts were again referred to, to ensure that analysis and any interpretations of data took into account the context in which they occurred. Within each case and theme participants' perceptions, views and responses were tracked, compared and contrasted. Any patterns, connections and associations were searched for and attempts were made to find explanations for these within the data itself. On immersion into the charts it was possible to see patterns and links, make further abstractions and identify additional themes than had been possible through the transcripts and indexing alone. For example, the themes of 'social comparison' and 'sharing' emerged primarily from this process.

For audit purposes, the charts and the findings emerging from them were presented to the thesis supervisors. Initial feedback suggested that they were focused too much on individuals and failed to capture both the patterns and diversity evident in the data. This led to a revisiting of the themes and incorporation of both patterns *and* individual variations being agreed upon for presentation in the findings, which follow.

5.3 Findings

The main aim of this study is to understand partners' perspectives on the factors that influenced their participation in the programmes and psychosocial and communicative

change. Table 2.1 summarises the themes relating to this aim that emerged from the data, and which are explored below. It should be noted that not all data sets featured referents to each theme, and therefore the data's representativeness across participants cannot be assumed. However, to enable judgement of this, the number of participants contributing to themes is provided in the text. Verbatim quotes are provided throughout to illustrate both patterns and individual variations within themes, and to facilitate judgement of any interpretations of the data⁶. To facilitate tracking of individuals verbatim quotes if desired, participants' pseudonyms are provided at the end of quotes as well as in the text itself. In themes where differences were found between the spouses and the daughters in the study, findings regarding the spouses are presented before those about the two daughters (Jenny and Denise). Where responses were felt to be influenced by the interviewer, Lauren's comments (preceded by 'L') are also included. The section below begins with an exploration of the interviewer's role and impact on the findings.

Table 2.1 Factors influencing attendance, participation and change in the SP and CP: themes and sub-themes

Factors related to the content and organisation of the programmes
Information giving
Positive aspects
Negative aspects
Videos and role plays in the CP
General organisational factors
Timing
Expectations
Session length and number
Number / mix in the group
Session / programme structure
Therapist's contribution
Factors related to individual circumstances
Every day life
PWA's reactions to the project / their spouse
Factors related to group and personal processes
Social comparison
Sharing
Issue unique to Therapy Order 2: dominant group member

⁶ Verbatim quotes are italicised. Stressed words are underscored. Text between [] is contextual.
... indicates elision

5.3.1 The role and influence of the interviewer

To facilitate an understanding of the biases or influence that Lauren brought to or had on the interviews, interpretation or presentation of the findings, Lauren's own contributions during the interviews are now explored.

For the large majority of the time Lauren asked open-ended questions, was an attentive listener, and gave the participants sufficient time to respond and probed responses in an attempt to obtain detailed answers. However, she did not adhere consistently to these traditional practices of conducting in-depth research interviews (Smith, 1995).

Occasionally she asked leading questions, and let answers go without probing, which prevented the meaning behind some responses from being fully explored at the analysis stage.

Only one interviewee, Amy, appeared initially reticent about discussing her fellow group members or potentially sensitive issues, and was worried about being seen as too opinionated. However, she trusted Lauren's encouragement to be open and honest. At no point did Amy or anybody else become overtly upset during the interviews, or explicitly refuse to answer questions. From their responses, disclosures and questions to Lauren it was evident that the participants treated her less as part of the research process and more as an equal. That is, they perceived Lauren as a partner of a PWA like them, as somebody with whom they could re-live or share their experiences and views and, in some cases, attempt to make some sense of them together with her. On balance, the nature and content of the exchanges suggest that Lauren's role as interviewer should be recast as 'discussion-leader' and, to some extent, participant. In many ways, then, Lauren can be considered to have advantages over a 'neutral' researcher. Her own disclosures often encouraged further disclosure by the interviewees. In tracking her contributions it could also be seen that some participants disagreed with her comments or suggestions. This implies that acquiescence was not a *fait accompli*. However, her contributions are included in the illustrative quotes in cases where her influence was possible or evident. Appendix 2H summarises Lauren's disclosures and evaluations during the interviews, the contexts in which they occurred and the influence that these had on the participants' responses. It is hoped that this will facilitate further understanding of Lauren's own biases and views about the programmes, and therefore aid reading and judgement of the findings.

5.3.2 Factors related to the content and organisation of the programmes

This section describes the role that the content and organisation of the programmes played in promoting or inhibiting partners' attendance and participation in the programmes, and their effects on psychosocial and communication change. These factors have been separated from those of group/individual processes in an attempt to differentiate the mechanisms which contributed to partners' experiences and evaluations of the programmes, even though links between them were evident and are explored where appropriate. 'Attendance' is also differentiated from 'participation': attendance can be taken to mean turning up at a session, whereas participation indicates a degree of involvement therein. This differentiation has occurred because the data suggested that partners perceived them, and the factors influencing them, as different.

The content and organisation of the programmes are described fully in Study One, but for convenience are briefly summarised here. Both the SP and CP ran for eight weeks, for two hours a week. The aim of the SP was to provide information about stroke and aphasia and promote mutual support and opportunities for group problem solving of psychosocial issues. The aim of the CP was to enable partners to gain insight into their conversation patterns with their PWA. The programme involved partnerships video-recording their conversations at home. These were then observed by partners in the group to promote awareness and discussion of conversation patterns, and as a catalyst for strategies for change where desired. Role play, verbal and written information and practical activities were designed to aid reflection and learning.

Table 1.8 in Study One shows that participants' weekly attendance at the sessions was largely consistent, with one exception: TO2's Amy attended five out of eight CP sessions, but attended only the first session of the SP which followed, although she never actually withdrew from the study. All participants completed the two programmes and all assessments, with the exception of Gwen, who left the CWC project after the post-CP assessment point. Therefore, exploration of factors associated with non-attendance/withdrawal is purposely related primarily to Amy and Gwen.

Comments suggested that factors related to content and organisation of the programmes had minimal effect on attendance, but greater effect on participation and change. Everybody provided both positive and negative comments about aspects of the

programmes, either without prompting or in response to specific questions. Patterns were evident across the majority of the participants for some themes, but others featured marked individual variations. Factors that positively and negatively influenced participation and change within both programmes are now described.

Information giving

- **Positive aspects**

Information giving was a major component of the programme content and weekly sessions. Comments from all bar Gwen, Ursula and Amy suggested that information given in the SP sessions encouraged participation by promoting reflection and personalisation of the information, which then led to sharing and comparing views and ideas. A quote from Judith illustrates this:

I found they [the sessions] covered really everything... [we were] basically keeping to the actual subject [then] both Fatima and myself used to say 'oh yes! oh yes that came up, that happened!', and then you'd describe what happened
(Judith)

It was evident from the comments of all participants that they perceived they had learnt new knowledge about stroke and/or aphasia as a result of the information they received in the SP. All stated they had found the information easy to understand. The quotes below are representative of their statements and the range of factors which contributed to the perception of, increased knowledge. These included participants' interest in the technical aspects of what they were learning and the comprehensibility of information given by the therapist and in written form.

What was extremely interesting was the immense variety of types of dysphasia, I'd never thought about it... Sarah actually went through it technically, you know... things like jargon (Tina)

... all the questions and the little tests we did were explained really well, with drawings and that, in detail, I found it very easy (Judith)

I think it was brilliant, I really do, Sarah... showed us so much... I knew nothing about [dysphasia] until I went on the course (Vera)

Judith and Fatima said that prior to the group they were anxious about their husbands having further strokes. The quotes below illustrate how the information and practical advice received during the groups reduced this anxiety. Judith's quote also suggests that she perceived her husband to have indirectly benefited from her participation in the programme:

... Judith and myself had the same comment, because the very first time that Jack had the stroke... she didn't know also what to do, but when we were in the course, oh this is a great help to us, now we know what we are doing if something happen again (Fatima)

... I didn't want to restrict him going train-spotting, but I was always glad when he came home, tended to get worried if he was home late, but Sarah gave him a card to put in his bus-pass, and I put his name and address in it and everything. That was one really good thing...I felt secure... Overall... we've both benefited from it... it was helpful for him, me knowing things (Judith)

As only Judith and Fatima discussed reduced anxiety as a direct result of receiving information, it is not known whether this positive psychosocial change was perceived by others.

Every participant commented on one or more aspect of positive communication-related change as a result of information given in the CP. Responses clustered around five types of change. The quotes featured below are representative of both patterns and ranges of responses within each type, and the number of participants providing related comments is provided in brackets. Table 2.2 summarises the different changes reported by each participant.

- Increased understanding of PWA's aphasic difficulties (3)

... I understand now more about how difficult it is for him, and I tend to be easier with things, not so demanding...I let things slip by that normally I would wanna get to the point of (Judith)

- Increased awareness of own/joint communication style or patterns (10)

One of the problems was that, right from the start I was always too keen to give her the right words that she was stuck on... I found you must give them time
(Kurt)

V: ... you're so used to talking... I talk all the time, these things you don't realise because you do them so automatically yourself

L: Yes, so one of the nice things about it was making you more aware of, reflecting on what you're doing

V: That's right (Vera)

- Changed communication through new strategies learned and reduced communicative tension (5)

When I'm in the kitchen and call things to him, he can hear my voice but can't distinguish what I'm saying, so now I come in and say it or I leave it till I've finished what I'm doing (Judith)

It was good to know about this repair situation... if I said the wrong thing he gets very irate... until I did the sessions I found that I wanted to retaliate because he would be having a go... I just actually walked away from it this morning and left it (Vera)

- New or reinforced strategies for aiding communication breakdown (4)

I may have known some of the things beforehand but I think it certainly reinforced strategies... if we encounter a stopping point then I can draw on something I've learnt I think (Tina)

- PWA's increased confidence/competence in communicating with partner/others (5)

... by the time we'd finished the whole of the project... he was quite good, not 100% but he didn't feel that he needed [further speech therapy] (Judith)

L: Will he start conversations with you?

U: Yes, he's been a lot better recently, and he will go out and have a word with the neighbours (Ursula)

Vera suggested that the changes she noted in her husband's communication gave her hope for the future and had helped their relationship:

L: *You've told me about how he will speak a few more words... so you're seeing some changes*

V: *Yes definitely, that's right*

L: *And I think that's what's giving you some hope*

V: *That's definitely- we are definitely doing better now (Vera)*

It is not known whether Vera would have said these things without Lauren's prompting. Fatima also implied that communication changes had helped their relationship, saying:

... it change a lot because we can talk now (Fatima)

No other participants made direct comments about communication-related changes having had an impact on their relationship. Though the data here may suggest that positive communication change may be beneficial in the greater psychosocial sense, further research explicitly focusing on the links between communication change and relationships is required.

One aspect of both programmes was the provision of a handbook containing handouts from each session. Six participants suggested that this was a useful source of information outside of the sessions, or was used as a revision tool between sessions or once the programmes had finished. Three suggested their PWA and/or other family members had shown interest in the handbook. Nobody commented negatively about it.

- **Negative aspects**

Three participants, Kurt, Ursula and Amy, made negative comments about the information they received in the SP. Kurt found it too 'academic', and suggested that the CP had been more practical and useful:

... when we were discussing the defects in language, it got a bit involved for me... rather academic... perhaps I was looking for something more practical... having some lessons in how to cope, put into practice what they were suggesting... I felt the second half [ie CP] was getting nearer to the target of what we wanted to do... because it was coming round to that sort of thing and I was seeing other people's ideas of it (Kurt)

For Ursula, aspects of the generalised information she received in both programmes caused her to worry:

...in some ways [the information in the SP] was a bit alarming because... I was sort of finding out things that could happen, but hadn't happened, you know, like epilepsy and the TIAs

[The information in the CP] sometime, made me worried because I sort of began to feel that up until going to Sarah's group, I'd sort of been doing it all wrong... you know, the communication thing... But I must say that the thing I found really helpful was the sort of instructions she gave for each couple, you know, with their particular problem, what to do (Ursula)

Ursula said that her anxieties, provoked by information given, usually surfaced *after* the group, when she had had a chance to reflect on it at home. She did state that this feeling of doing everything wrong was 'the story of her life', so it is possible that her own personality contributed to her worries. As no other participants provided related comments, it is not possible to know whether Ursula's feelings were shared. However, her example highlights the importance of recognising that information – particularly that of a general nature – may be interpreted negatively, and suggests that clinicians should build in adequate avenues for exploring potential responses to information within and across sessions to prevent unnecessary anxiety.

For Amy, the information given appeared to challenge her avoidance of looking at the loss she felt for her pre-stroke husband:

... I just felt it was all going through what was wrong...I mean I know Paul is dysphasic, but I don't know why that... I just felt that I didn't need to be told... didn't want to be told...you know I'd gone from this very active man, that was really strong and able to do so much to someone who'd lost confidence and his strength (Amy)

It was evident from Amy's comments that her reluctance to hear about and discuss aphasia in relation to her husband contributed to her non-attendance.

In the CP, it was evident that some partners did learn strategies in the sessions to try with their PWA, but that other factors inhibited their use. Two suggested that the

strategies they learnt were inappropriate or were unacceptable to the PWA. For example, Tina felt that her and her husband had 'gone way beyond the stage' of using strategies such as gesture for everyday conversation. Gwen, who perceived her partner to be affected more severely and differently than the others in her group, felt that strategies suggested either did not apply to her situation or would not be useful because of the severity of her husband's impairments. She said the course had not changed the way she talked with her husband. However, both Tina and Gwen felt they had learnt strategies to use as 'back up' for communication breakdown.

Table 2.2 *Type of communication-related changes reported by each participant as a result of the CP*

	Tina	Carole	Kurt	Judith	Fatima	Gwen	Ursula	Vera	Jenny	Denise	Amy
Increased understanding of PWA's aphasic difficulties				✓			✓	✓			
Increased awareness of own/joint communication style or patterns	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓
Changed communication through new strategies learned and reduced communicative tension			✓	✓	✓		✓	✓			
New or reinforced strategies for aiding communication breakdown	✓			✓		✓			✓		
PWA's increased confidence/competence in communicating with partner/others				✓	✓		✓*	✓			✓*

* Change not definitely attributed to programme

Videos and role-plays in the CP

Several aspects of the content of the CP were evaluated positively by some partners but negatively by others. These polarities were particularly noticeable in relation to making and observing video recordings of conversation and doing role-play activities. Appendix 2I summarises partners' responses to these, and illustrative quotes are provided below.

Comments from everybody about recording their conversations suggested that the process resulted in differing degrees of stress. There were six different factors that contributed to this:

- a perceived lack of anything to talk about
- perception that they were unable to communicate naturally in front of the camera
- shyness
- a desire for the conversation to come across in a certain way
- fear of operating the equipment
- anxiety about the conversation being 'assessed'.

Two partners, Tina and Carole, suggested that the conversations they recorded were very different to the type they usually had with their partners. The remainder said that what they had recorded largely captured their everyday communication patterns or style. Despite the stresses of recording videos, all but Carole and Jenny commented on the usefulness of observing the videos in the sessions. Most valued being able to observe their own patterns of communication and see examples of successful communication and areas for change, though Gwen and Amy talked of learning more from others' videos than their own. The two examples below capture the variety of responses to making and observing videos:

... as for the bad part, the videoing, that was horrific for us, we just didn't get on... we just couldn't cope with that... it just felt so unnatural to sit there, because we're not the greatest conversationalists, I mean after you've been married all those years, it's hard isn't it... Maybe it's 'cause I don't like to express my feelings on tape or video (Carole)

L: *[When you recorded your conversation] was it easy or difficult?*

- J: *Well it was easy enough but when you haven't used a thing like that you keep thinking have I got it set up right*
- L: *What you talked about, was it like ordinary everyday conversation or not?*
- J: *Oh yes, very relaxed yes... Sarah was amazed, we did three quarters of an hour and she couldn't believe the number of subjects we covered*
- L: *Is that what you do in everyday life?*
- J: *Yes*
- L: *Did you think it was useful, in the sessions when you saw it, or not?*
- J: *Oh very very, that was very helpful... Sarah pointed out that Jack wasn't facing me... he had his head turned and I could see it was uncomfortable for him, so we altered that and it works better now (Judith)*

There were both positive and negative reports of the use of role-play. All but Tina, Kurt and Fatima suggested they did not enjoy doing them. However, they were recognised by Tina, Judith, Gwen Ursula and Jenny as valuable for gaining awareness of aspects of aphasia and their PWA's post-stroke communication experiences. Participants in TO2 reacted most negatively to the role-plays, which were introduced in week two of their programme. Their comments suggested they felt embarrassed and inhibited by role-playing with people they barely knew, and they recommended better explanations of roles and using them later in the programme, or, preferably, not at all. Jenny's quote captures both the positive and negative aspects reported:

... the only thing we really didn't like was the role-play... I felt embarrassed ... but I think the role play plays an important part because it helped you to understand what it's like not to be able to answer back (Jenny)

General organisational issues

The following points summarise participants' views or recommendations about general content and organisational issues. Though on the whole these did not affect attendance at the sessions, they did appear to affect levels of participation in the programmes and perceived benefits, and may therefore have implications for future programme planning.

- **Timing**

Several partners made comments to suggest they would have benefited from receiving the programmes earlier. Regarding the SP, Fatima, Vera and sisters Jenny and Denise, whose partners' strokes were eight, 14 and 16 months before the programmes, said they would have preferred to receive the SP much sooner. Their comments – plus those of all but two others - suggested they had received too little information and support from services prior to the programmes, particularly in the acute stages. They cited a need for early information about how to cope with stroke, help their partners and reduce their own anxiety and isolation. These comments from Vera and Denise were typical:

I didn't know anything, but nobody explained anything to me either... you can read a book but you don't know how it relates to you...I was just so ignorant
(Vera)

I think the first six months was a nightmare 'cause we didn't know where we were going or how long it was gonna be this nightmare for... there was just nothing (Denise)

Comments from Tina, Carole, Jenny and Denise, whose partners' strokes had occurred 57, 35 and 16 months before the programmes, suggested that the CP had come too late for them to make changes to the way they communicated with their PWA. They perceived that they had adapted adequately to communicating in the presence of aphasia prior to the programme, and that the habits and patterns they had grown used to were now resistant to change. This quote from Carole represents others' comments.

I think it would have been more beneficial just after he'd had the stroke, because I think after you've been with someone that's had a stroke two years hence, you've got into your own way of communicating and we did quite well on our own, and I suppose once you've got one way of doing it you're inclined to stick to it (Carole)

One thing that was not explored in the interviews was these partners' perceptions of their PWAs' perceptions of communication and strategies used. However, it was evident from the interview data that some strategies - such as repeated hint and guess

sequences or encouraging long correct production sequences - had the potential to challenge the PWAs' communicative competence and thus reduce their confidence and self-esteem.

Ursula and Gwen, on the other hand, suggested that the programmes came at the right time post-stroke (18 and 19 months respectively). Gwen's withdrawal from the programme should be borne in mind however: she may have considered the timing to be right, but additional factors obviously made this equivocal. Amy suggested that the programme timing coincided with the need for her to be at home to deal with workmen, and that this was a reason for not attending sessions.

Timing of programmes is obviously a complex issue, as the following extract from Tina and Lauren's discussion shows:

- L: ... all our partners had their strokes some time ago
- T: Mm, I just wonder what would have happened if this had taken place within a few months of them having had a stroke... I might have used the course in a different way because obviously after five years, to a certain extent, you're set in your ways... and you can't really go back quite so easily than if you're at the unformed stage, I think maybe a few months-
- L: -So it might have been nice for you to eh-
- T: It might have been, but I don't quite know at what stage because, this is the really difficult one I think because, if it was a really shattering stroke, then the psychological impact of it, you know, you're still in a sort of state of shock and not receptive from that point of view, perhaps still in a state of denial, and that creates a barrier, so I think it's difficult probably to identify, certainly on a routine time-scale, like every stroke victim will be most receptive at six months after their stroke you know
- L: So ideally it would be useful if the couple could decide, or someone could help them decide, that this was the right moment (Tina)

There is an obvious need for further consideration of intervention timing and the links between organisational and personal process issues involved.

- **Expectations**

Expectations are featured as an organisational issue because the data suggested that information given to participants prior to them joining the programmes influenced their expectations. However, it is acknowledged that prior personal experiences also influenced expectations.

All but Fatima provided comments about their pre-programme assumptions, expectations or anxieties, though only two – Amy and Tina - revealed that these influenced their attendance or participation. Amy was ‘quite looking forward’ to joining the group, and thought it would be ‘an afternoon out to meet other people who had been similarly affected’. Once underway however, the participants sharing and discussing their problems repelled her. Related to this, she stated that she didn’t know if she ‘really went there to talk about my problems’, suggesting that the group did not meet her expectations. She agreed with Lauren’s suggestion in the interview that this was one factor in her non-attendance.

Tina, on the other hand, was less keen to join. She was afraid the course would be upsetting, based on her negative experience of joining a carer’s group six weeks after her husband’s stroke, which she felt confronted her with the severe and long-term effects of stroke too soon, when she was still in a state of shock and denial. However, she commented that she found talking to other partners in the programmes ‘quite reinforcing’ and not the negative experience she had anticipated.

All participants in the CWC project were given verbal and written information about the content and structure of the programmes prior to joining. However, the data suggests that some felt insufficiently forewarned about what would happen in the sessions, and therefore experienced some discomfort as a result. This highlights the importance of clinicians providing as full and detailed information as possible about intervention before it begins, to enable participants to make an informed decision about joining and to be aware in advance of the processes which may occur.

- **Session length and number**

Regarding length of the sessions, Judith, Fatima, Vera and Ursula would have liked longer than two-hour sessions, because they were enjoying the time at them, though they were happy with the number. Jenny and Denise suggested that attending 16 sessions was a hefty commitment for people needing to find care for their PWA.

- **Number/mix in the group**

Judith, Fatima and Vera felt they would have liked more participants in their group, as they perceived they could have learned more from additional partners' experiences. Ursula, Vera and Denise would have liked to gain insights from others 'further down the road'. It was obvious that some felt isolated because their needs were different to others (though this was related to the process of social comparison, and is therefore discussed further in Section 5.3.4, it is also discussed here as organisational issues are implicated). For example, Gwen suggested she was different from her fellow participants because of the nature of her husband's impairments. Kurt said that he felt inhibited by being the only male in his group and that he felt some of the information was aimed more at the women than him (though none of the women said Kurt being in the group was inhibiting). The two daughters perceived differences between them and the spouses in their group, who were older than them and living with a PWA, though this did not affect their attendance. They also felt that some of the information given at the group was aimed predominantly towards the spouses. It is possible that this affected their levels of participation, though this was not discussed during the interview. These findings suggest that different 'types' of partners may have different needs both outside and within sessions. Further research is required to attempt to understand these different needs more fully and how to accommodate them within group interventions.

- **Session/programme structure**

Tina and Vera stated they would have liked more opportunity for discussion of problems and less information-led time, though the remainder was happy with the balance. Gwen said that she would have been happier and learnt more in the CP if less time had been spent talking. She suggested that members of her group would have benefited from receiving the SP first, as this would have allowed them opportunities to

discuss and problem-solve their psychosocial concerns, which in turn would have enabled them to focus more on learning about conversation later. As it was, she saw that their need for talking had not been fully met because of this organisational imposition. Although no others in the group mentioned this in the interviews, this was a matter of discussion in the sessions. My view as the therapist mirrors that of Gwen.

- **Therapist's contribution**

Comments from all participants about the therapist reflected that she was perceived as an important aspect of the group's organisation, structure and dynamics. Positive comments clustered into two broad types, with five participants reporting that her interpersonal style had enabled them to feel relaxed and comfortable about contributing in the sessions, and six commenting on the clarity of information presented. Jenny and Denise provided negative comments, related to the therapist's insufficient explanation of role-plays.

5.3.3 Factors related to individual circumstances

Factors related to individual circumstances outside of the programmes influenced participation and change. These are now discussed.

Everyday life

It can be recalled that Amy was the only person who did not attend the sessions regularly, and that the content of the programmes and her reluctance to discuss her problems during the sessions – which she said she had not expected to do – contributed to this. It was evident that everyday life events coinciding with the programme, and her anxiety about leaving her husband, were also factors in her non-attendance:

I didn't go regularly because I was tied up with other things and it was just the way I was feeling at the time. I was worried all the time [about leaving Paul] and there was the builder and the gardener... and all that was taking place while Sarah was holding her classes, so it all worked out at all the wrong time... I'm glad I went, I wish I could have gone a bit more frequently, it's just the way the circumstances, you know, life worked out at the time (Amy)

Gwen and Vera also expressed anxiety about leaving their husbands alone while they attended the group. Their fears for their spouses' safety were never realised, and they both attended regularly despite them. It is possible that their participation in sessions was marred by their anxieties however, or that in leaving their husbands, the partners promoted independence for both of them, or conversely, anxiety in the PWA. These issues were not explored in the interviews but indicate a need to consider care for the PWA when planning and organising partner programmes.

Two partners, Carole and Vera, suggested that attending the programmes resulted in a sense of burden, as illustrated here by Carole:

... Nick was at a class in the afternoon and I'd have to get him home and get his tea and get out and all that, and you'd think oh God I've gotta go to the group and I suppose sometimes I resented that (Carole)

Comments from Vera suggested that daily tasks such as housework and various medical appointments for her husband, which tired her, stopped her making the most of the sessions. It was evident too that, although she saw the need to make changes in her life to help herself, daily life activities prevented her from making them, as this extract illustrates:

It was strange [going on the course] at first because I hadn't had any time, I don't even now. Sarah wanted me to go and carry on, like go out on a Tuesday as if I'm still on the course, so that I get a break, it hasn't happened because there's always been something ever since (Vera)

Kurt also made comments related to everyday life stopping him from making changes, which would benefit his own well being. Because only four partners contributed to this theme it is not known whether their perceptions and experiences were representative of the group.

PWA's reactions to the project / their spouse

All but Gwen and Ursula commented on the degree of their PWA's involvement in the CWC project, though only Kurt, Carole and Vera – now discussed - suggested that their involvement had any negative influence on participation or change.

Kurt suggested he did not discuss the programmes much with his wife because of her negative response to his own involvement in them:

I think it was good but it did provoke a lot of argument, or differences of opinion... I did [talk to her about the group] at times, but she's made up her mind that it was a waste of time me going, I'm as bad as I was when I started. But I mean, no I got a lot from it, but a lot of it was controversial to Megan... on the other hand I've got to be fair and say that some of the things that we did in the group, I found it difficult to put over to Megan... sometimes she'd say I don't want you talking about me to anybody and everybody (Kurt)

Kurt said that prior to the project he was struggling with Megan's mood swings and tensions arising from communicating and role changes post-stroke. The quote above suggests that the course, and Kurt's attempts to include Megan in it, to a degree inflamed those tensions. It can also be seen that Megan's responses may have inhibited changes in their communication from being realised, even though Kurt felt he had learnt new strategies:

... I think [I was] relatively nervous of trying some things because sometimes you only need to say the wrong word or wrong hint, and you're in trouble, you've got an argument on your hand (Kurt)

Although not explored in the interview, it is possible that Megan responded as she did because she felt excluded from the project.

Carole and Vera also suggested that the reactions of their husbands inhibited communication change. Although Carole suggested that she and her husband managed communication well prior to the course, she also implied that factors related to his

personality and their relationship influenced the degree to which the strategies she learnt could be implemented:

I think when someone suggests something else, I mean Nick is very obstinate, and if he don't want to do anything he won't, and I mean some of the points that Sarah brought up yes, they're very good for gesturing and that, but to get them through to Nick and to do them, a total waste of time (Carole)

In the following extract from Vera's discussion with Lauren, Vera attributes Bernard's negative reactions to her use of strategies to his pre-stroke communication style and their pre-stroke relationship:

- V: ... I tried using [strategies] frequently, didn't always get a very good response, 'cause Bernard doesn't really talk... he's just not bothered...
- L: Yes... so improving a conversation with somebody who doesn't want to talk to you does seem to be a bit of a, heh heh, catch twenty two
- V: Yes, that's right, he's not bothered to talk with me

An alternative explanation for the above PWAs' negative reactions to strategies used by their partners may be that these strategies in some way exposed them as being less than communicatively competent. However, this was not explored in the interviews.

Although Carole did not discuss the course a great deal with her husband, stating the agreement to preserve confidentiality of the group as the reason, she did sometimes talk to him about it:

[I told him about] what we saw on video... I said to him you know, at least I wasn't alone in my thoughts...other people thought the same way I did (Carole)

Carole had previously not discussed her feelings with Nick. The quote above implies that the programme had resulted in a change in this aspect of their relationship, and is an example of where content (ie video) promoted personal process. The impact of this change on both Carole and Nick was not explored in the interview. Carole did however state that Nick's perception of her interest in him, proven by attending the course, had had very positive effects:

... the improvement in him has been tremendous, and I think because he thought I was going and doing something, that he felt good as well that I was actually going and maybe taking an interest in him (Carole)

5.3.4 Factors related to group and personal processes

This section explores how partners' attendance at and participation in both the SP and CP sessions, and psychosocial and communicative change, were influenced by group and personal processes. Group processes are defined as interactions between participants in the sessions, and personal processes are defined as individuals' feelings and behaviours within or related to the sessions. Unsurprisingly, during sessions personal processes often created group processes, and vice versa. Because of this, findings about both are presented together. It will also be seen that a range of factors were perceived by some participants as positive and facilitating, but by others as negative or inhibiting.

Two major themes captured partners' perceptions of their own and others' behaviours and feelings during the sessions, and their perceptions of commonality and differences. These were 'social comparison' and 'sharing', and they related to both group and personal processes, and to each other. It is in each of these themes that group and individual processes become so intertwined that separating them for presentation purposes would be futile and misleading. The findings below also illustrate the contribution that programme design and content made to these processes. Because of the volume and strength of referents to social comparison in the data, the discussion of this factor is more detailed and in-depth than for others.

Social comparison

Everybody made comments that suggested that being in a group led them to embark on a process of comparison with other members. They compared thoughts, feelings and personal situations, their PWA's impairments, their communication style, strategies and relationships. These comparisons influenced partners' attendance at and participation in the sessions, their responses within and outside of the sessions, and changes in

individuals' practical and emotional responses to stroke and aphasia. Comparisons took three main forms, which are now discussed.

- **Upwards comparison**

Three partners made upwards comparisons, that is, they compared themselves with others whom they considered to be more fortunate (Suls and Wills, 1991). Upwards comparison had predominantly negative outcome. Perhaps the most drastic was experienced by Gwen, whose comparison of her husband's communication and physical impairments and their resulting living situation, with those of the rest of the partners in the CP, was a major factor in her leaving the CWC project. This extract of Gwen's discussion with Lauren illustrates the complex process that began as a result of viewing on tape, and subsequent discussion of, partnerships' conversations (an example of content creating personal process). It also introduces Gwen's reactions to another group member's behaviour.

G: *I got depressed after the first session, when I saw these other people's videos, and then I thought hang on a minute, the majority of people I could like... I shouldn't say that I didn't like the other party but-*

L: *-Say what you like, it's your experience, you had it, heh heh*

G: *So I thought well, give it a go... well then, at the second session, somebody said quite inadvertently something their husband did, and I thought to myself, oh gosh, Maurice could never do that, and so the depression started coming in at that point*

L: *Right, 'cause you were seeing people who'd had stroke, but who in most ways were much better?*

G: *Yes, 'cause it turned out, of all the group there was only one other man, who was a lot older than Maurice, who was in a wheelchair, that was the first thing that struck me, and then I think one of the others said quite casually something about, oh my husband can go up to the bar and order himself a drink... and I thought to myself there's no way that Maurice could do that*

L: *You're telling me as though it kind of really struck home to you*

G: *Well it did!*

- L: *As well as being aware that he was worse it suddenly brought it home to you in a powerful way*
- G: *I-it- I think you-you've hit the point*
- L: *Yeah*
- G: *When I'm here all the time with him, I'm so used to the way things are now, perhaps I don't think about it too deeply... but it kept coming back to me on the course... well I came home one night and I said to my son, I feel more depressed at the moment than when Dad was first ill... (Gwen)*

This extract highlights the dramatic effect of Gwen's upward comparison. The realisation from the process had the effect of breaking down the 'get on with it' response that she said she had developed in the aftermath of her husband's stroke. It should be noted that the stroke had coincided with Gwen's father's developing illness and subsequent death. This resulted in Gwen replacing mourning her losses with constant practical activity around her husband and father, and suspension of negative thoughts. Gwen agreed with Lauren's suggestion later in the discussion that the process she had gone through in the sessions 'seemed to be bringing up some grieving that she hadn't finished', about her husband, father, and lifestyle losses. It is not known whether Gwen would have stated this without prompting. However, Gwen's comments above, and later in the discussion, suggest that this was likely. Gwen did state that the depression that had set in after comparing her situation with others was one reason for her leaving the group, although she primarily attributed her withdrawal to Vera's behaviour, as will be discussed later. In notes made after the discussion, Lauren suggested that Gwen had put her anger onto Vera and used this to rationalise her departure from the project, to protect her from falling further into depression, and to maintain her self-esteem. Lauren felt that in one sense Gwen needed to be left to get on with the defences she had previously developed and so desperately needed. These interpretations are interesting, but as they were not explored with Gwen during their discussion, can only be tentative.

Tina also felt negative effects of upwards comparison, stating that she felt envious about activities that other partnerships could do that she and her husband could not. For Vera,

again through observation of others' videos, the process led her to perceive her and her husband's relationship as negative compared with the others:

[Watching the videos] was very enlightening...you could see the depth of people's- not just anxiety, but the depth of actually how people got on together, like a close relationship... I could see what I call love there, or the relationship was there, of other people, which mine seems to be more like: we're here... we're not close is what how I feel (Vera)

The above comparison may also have influenced a more positive effect: Vera's quote below is a strong indication of the hope for her and Bernard's future that she developed from being on the course. It is not possible to know from the data whether this was a direct result of the comparison process or because of her perceptions that they were 'doing better', as reported earlier.

I try hard, I try so hard because I feel now, at the end of the day, I've obviously got to gain something from it, even if it's just our own, being together, you know, that we could build up on something... we don't know how long we've got together now, so we've got to make some effort, even if it's all on my side and not Bernard's (Vera)

- **Downwards comparison**

Five participants embarked on a process of downwards comparison, that is, in comparing themselves with others, they perceived the others as worse off than themselves (Suls and Wills, 1991). This had positive and negative effects.

Although Tina did feel worse off than others in her group, comparison with partnerships she observed on a teaching video, whom she perceived to be worse off than her, enabled her to evaluate her situation somewhat more positively. She stated that this made her feel 'not the bottom of the heap'.

Ursula, Denise and Jenny's comparison with others enabled them to evaluate their own situations and emerge feeling positive:

It was nice to meet the other wives and hear about their problems, you know, it makes you realise you've got a lot to be thankful for (Ursula)

We thoroughly enjoyed it in as much as... seeing other people... we'd just come back thanking our lucky stars that there was us three [children who cared for their father] (Denise)

Although Denise and her sister Jenny felt their communication or life situations had not changed as a result of the course, the quotes above and later illustrate that they benefited in other ways.

For Amy, the process of downwards comparison, together with the information she was being given and was sharing with other participants in the group, appeared to have had mixed effects. Again, it caused her to think about her and her partner's situation in relation to others, but this was not something she wanted to do or expected from the programme.

... I think what struck me about some of them was that, I thought I was in a bad way [mentally] but some of them were in a far worse way than what I was, and I just didn't want to meet that at the moment, you know, I just didn't want to think (Amy)

It is possible that, like Gwen, the process challenged her response to stroke and aphasia. It was evident that in one sense, Amy was driven to restore her husband's skills and confidence. This was quite different from the dwelling on difficulties, which she perceived was happening in the group and which she recognised as another contributing factor in her irregular attendance. A positive effect of the comparison process was Amy feeling that she and her husband were better off than others:

I realised I'm one of the lucky ones, heh heh heh... no I'm not lucky, but I don't think he's as badly affected as what some of them are (Amy)

This realisation, in turn, may have strengthened her resolve for moving forward with life with aphasia. In answer to Lauren's questions about whether she and her husband

had changed in any way as a result of the programme, Amy said she found it difficult to know whether recent improvements she'd noticed in Paul were as a result of her going to the group. She did say, however:

... perhaps it gave me a bit more fighting determination to not let things just roll on, that you've got to do things you know, and help yourself (Amy)

This quote suggests that Amy's non-attendance at the group should not necessarily be interpreted as a negative occurrence. Rather, it could imply that she was able to turn aspects she perceived as negative into a more positive attitude or outcome for herself. An alternative is that she was just wishing to say something to please the interviewer, though given her honesty to that point, this is unlikely.

- **Sideways comparison**

For Carole, Kurt, Ursula and Vera, the comparison process led them to recognise similarities with other group members (sideways comparison) (Suls and Wills, 1991). This resulted in the normalisation and validation of their emotions or the development of new relationships. Through comparing, contrasting and sharing their reactions to and strategies for coping with stroke and aphasia, they found comfort, support and new ideas for living with stroke and aphasia. Carole said that sharing her thoughts with others who she perceived as similar to her was the most important aspect of the course:

The good bits, I would say, was being able to talk to other people, to see how they felt, and whether I was not alone in my thoughts as such, to the point I could kill him sometimes, that other people thought that way... And how other people coped, that is the bit I enjoyed the most, the bit when we talked amongst ourselves and to how we reacted and how we coped with them (Carole)

Although Carole had not been keen to join the study and did not feel that her and her husband's communication had changed as a result of it, the above quote suggests that the group was beneficial in an other way. Given her repression of feelings up until the time of the group, it should perhaps not be surprising that she relished the chance to 'have a moan', as she described it. It also confirms that she was able to benefit in some way from the programme three years after her husband's stroke.

The quotes below also illustrate how sideways comparison validated Kurt's situation and enabled Vera to feel less isolated in her lack of knowledge:

[Seeing videos of other people] were quite informative because it allowed me to be able to put our own situation in some sort of relationship to how other people were... I was looking for fitting our situation into other people's, seeing what they were trying to achieve or doing and where we fitted in to the sort of pattern
(Kurt)

... I do know with their conversation of different things they said, that a lot if it they didn't know, obviously any more than I knew (Vera)

The effects of Ursula's sideways comparison were mixed. In comparing herself with Gwen, she recognised experiences and responses they had both shared. This led to Ursula perceiving a sense of affinity with Gwen that was stronger than with other group members. This had both positive and painful dimensions:

... Gwen, you know, I was really sorry she dropped out because I felt she was the same with her husband as I was... her feelings and the way she treated her husband seemed to be the same as I was with Joe... whereas I think some partners think that perhaps you treat your husband too much like the kid glove
(Ursula)

The above quote illustrates how the relationship that developed between Gwen and Ursula fostered a positive sense of connectivity for Ursula but how this was upsetting when broken. It can also be seen that Ursula felt judged by others who she perceived were unlike her and Gwen. This sometimes prevented her from participating fully in sessions:

... sometimes I would sort of speak up about something then I'd think after I wished I hadn't... I just felt that perhaps others might have thought I hadn't got the right attitude (Ursula)

This is an example of perceived group process creating personal process. It should be acknowledged that no other group members commented on Ursula's attitude during

their interviews, so it cannot be determined whether they were judging her or not, or whether another process related to Ursula's sense of self was at work there.

Sharing

Another major theme related to group and personal processes that emerged from different subheadings on the charts was 'sharing', titled thus because this was the term used by several participants to describe the process of exchanging thoughts, feelings and experiences. This theme, and its impact on people's responses to living with stroke and aphasia, was introduced in previous sections, because sharing arose from both programme content and the process of comparison. However, because for some the process actually arose from being in a group setting, it is considered further here. Comments about the sharing process suggested that it resulted in three broad types of effects: learning new skills, development of awareness of, and relationships with, other group members, and actual/hoped for psychosocial change. These are now discussed. Space limitations prevent all comments being included, but Table 2.3 summarises the range of effects of the sharing process for different participants. Those quotes featured are representative of the overall picture, with comments about idiosyncratic effects highlighted.

- **Learning new skills**

All bar Tina, Ursula and Amy suggested that the sharing process enabled them to learn new ideas for coping and communicating, as illustrated below:

... we shared it, and if one did one thing another way and if we didn't do it, we could maybe adapt ourselves to that way (Carole)

...we were sharing our problems... we listen to each others and when we discuss all the matters in the session, yes this is what you have to learn so you can help your partner... (Fatima)

- **Development of awareness of and relationships with other group members**

Everybody made one or more comment suggesting that they had developed awareness of the needs, skills and/or difficulties of their fellow group members. For example,

Carole recognised Tina's frustrations at being stuck at home all day and Kurt's need to talk, and Tina defended Kurt's communication style, suggesting he shouldn't be expected to change. All but Gwen and Amy suggested that the sharing process resulted in perceptions of reduced isolation. Of these, all bar Tina, Carole and Kurt perceived this had also contributed to the development of significant new relationships with another group member, as the following quotes represent:

It was very interesting meeting other people on the course, because I think at the time you tend to think you're the only ones in this situation, you know, how on earth are we gonna cope with this... and you think oh yeah, I'm not the only one who's been in this boat (Jenny)

we wanted to sort of all get to the same sense of understanding... yes they're very nice... we were sharing something... the two girls [Jenny and Denise], they gave me their number (Vera)

- **Lifestyle change**

Comments from Carole and Kurt suggested that sharing ideas in the sessions promoted actual psychosocial change. During their discussion Kurt and Lauren reminisced about how during one session he had expressed anxiety about taking holidays with his wife for fear they would exhaust her. After advice and discussion in the group about trying a short break as a first step, Kurt and Megan took their grandchildren away to the seaside. An added bonus was that Megan organised a lot of it, which was rewarding for both her and Kurt, and how she had been more relaxed away from the pressures of home:

... she organised our holiday while we were there and that, though I did the original bookings... that was very good, she was a lot better (Kurt)

Amy also talked about feeling more confident to plan a holiday. It is acknowledged that she did not state explicitly that this planned psychosocial change was a direct outcome of the programme, but she had been highly interested in Gwen's description during one session of a holiday she had recently taken her husband on, and had sought contact information from her.

Perhaps the most marked psychosocial change resulting from sharing in the group was Carole's decision to agree to her husband getting a motorised scooter. This extract from her and Lauren's discussion illustrates the various benefits this had.

- L: *I thought the thing we all got excited about in the group was when Nick got his scooter*
- C: *Yeah yeah, one of the best things we've done, really has I mean, he's still going out on it when the weather's nice... the other day he said 'I'm going my scooter' and I thought alright fair enough... but it's getting dark at nights and there's no lights so I get a bit worried, but he's quite happy ... he'll take himself up into the city centre, so that is, you know, a good thing...*
- L: *... yeah, 'cause originally I thought you talked about it in terms of would it be a sign of defeat, to let him have one*
- C: *Yeah- no well not necessarily defeated, I mean I was just a bit apprehensive about it, but then we talked about in that session and as I say now it's lovely, he can take himself to class and as he said, well it's saving you keep taking me backwards and forwards, so I feel as if he thinks he's giving me a rest*
- L: *Mm, he is, and he's more of his own man I think*
- C: *Oh yes, he comes home- 'I'm going to do this' he says...*
- L: *Does that feel nice that you're back to you more equal ways?*
- C: *I suppose so, because you did, you was doing everything for him, to me it was like a role reversal, because Nick's always looked after me... and when this happened the onus was on me, so it's nice to think that he is- well I know he is coming back to more as he was because he's getting more pig headed, his usual self, heh heh*

The above extract shows the snowballing effect that began with Carole sharing her anxieties in the group: Nick gained more independence and confidence, Carole acquired some anxiety but also a reduced burden of care and a husband who was more like his old self.

Table 2.3 Individual effects of sharing with others in the group

	Tina	Carole	Kurt	Judith	Fatima	Gwen	Ursula	Vera	Jenny	Denise	Amy
New ideas for coping and communicating		✓	✓	✓	✓	✓		✓	✓	✓	
Awareness of needs, skills and/or difficulties of fellow group members	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Reduced isolation	✓	✓	✓	✓	✓		✓	✓	✓	✓	
Development of new friendships				✓	✓		✓	✓	✓	✓	
Actual lifestyle changes		✓	✓								
Planned lifestyle changes											✓*

* Change not definitely attributed to programme

Issue unique to Therapy Order 2: dominant group member

A recurring theme for members of TO2 was the effect that one particular member had on group and individual processes. This has been introduced in previous sections but is explored more fully here as the issues raised may have implications for future programme organisation.

Vera was perceived by all other group members as having a particular need to talk. Vera recognised her difficult relationship with her husband. Each week she dominated the group with lengthy monologues of her husband's past and current behaviour and attitude. Some members were able to accommodate Vera's behaviours in the group, and actually encouraged them. For others, particularly Gwen, Amy to a lesser degree, and sometimes to me as therapist, Vera was perceived as uncontrollably dominant and disruptive. As seen earlier, Gwen did have other reasons for leaving the group, but she primarily attributed her withdrawal to Vera's unremitting talking and constant interruptions and digressions:

... I got more and more fed up with her... you see, the very last session I attended, she was in full flow, and I thought I just cannot take any more of this
(Gwen)

As can be seen in this extract, Vera recognised her own verbosity, but not the negative effect this had on other group members:

- V: *Sarah was... good at putting us all back on track, especially me... 'cause I talked too much*
- L: *Oh right, did you feel you talked too much? Or did the others tell you?*
- V: *I know I talked too much, heh heh heh, I was excited ((lots of laughing))*
- L: *Right, did any of the others have the courage to tell you you were talking too much?*
- V: *Ehm, no I think, yeah it- no it all went down well because we did learn from one another a great deal* (Vera)

While it is possible that Vera lacked awareness, or had awareness but did not use it, the following extract suggests that her behaviour was due to an overwhelming need to tell her story. This story began with her husband having his stroke while they were on holiday in Greece, where Vera mounted a sole, month-long bedside vigil in a hospital where nobody could speak English to her. Although it is possible that Lauren's

contributions in this extract may have prevented Vera from disagreeing, Vera herself, other group members, and I, all perceived that telling her story was a pressing need.

L: *It sounds very nice to me that there was so much for you to learn, but the other bit that struck me was: nobody had given you the space to talk before too, so I guess there was that side of it as well*

V: *Well I did do, I annoyed Sarah probably heh, just for the fact that I probably did talk too much, but I did draw on the others, from things that they said*

L: *Did you?*

V: *Yes, and you realise you relate to what they were saying, which was good*

L: *Yes, and they do link together don't they, but I was just really struck by the fact that you wouldn't have anybody to talk to much in Greece, and then you came home and didn't have anybody to talk to, so I saw you as having two years of stuff*

V: *That's right, that's right yes (Vera)*

Participating in a support programme that facilitated Vera's talking about her experiences prior to being in the more focused conversation programme (ie as in TO1) may have been more useful for Vera.

Summary

The findings suggest that an interaction of numerous factors influenced participants' attendance and participation in the SP and CP and resulting change. These were related to the content and organisation of the programmes, individual circumstances and group and personal processes. In the next section these factors and the relationships between them will be examined in greater detail, findings will be linked to the extant literature and clinical and theoretical implications will be discussed.

5.4 Discussion

The main aim of this study was to understand partners' perspectives on the factors that influenced their participation in the SP and CP and psychosocial and communication change. The second aim was to evaluate the appropriateness of the study method for uncovering participants' perspectives and evaluations of the programmes. This discussion summarises the key themes found in the study and links them to current theoretical and/or clinical knowledge. Implications of the findings for clinical practice and future research are explored, as is the degree to which the aims of the study have been met.

5.4.1 Factors related to content and organisation of the programmes

The content and organisation of the programmes appeared to have less effect on partners' attendance at the sessions than it did on participation and change: most participants turned up for sessions regularly, despite some reported difficulties fitting in with the organisational structure of the programmes. The findings illustrate both patterns and individual variations within themes.

The factors that influenced both participation and change were the information provided in both programmes, recording and observing videotapes of conversation and doing role-plays during the SP, and general organisational issues. These are now discussed.

Information given in both the SP and CP had mainly positive but some negative effects. It was perceived by most as easy to understand and clearly delivered, though a couple commented that they did not enjoy the 'technical' aspects of the information. Most participants suggested they used the information to reflect upon and personalise the issues covered, and as a catalyst for sharing ideas. This suggests that the delivery of personalised information, based on Kolb's (1984) experiential learning cycle, which has been found to suit adult learners, worked effectively in the CWC project setting. Positive changes reported as a result of this process in the SP included increased knowledge of stroke and aphasia, decreased anxiety about the PWA's safety, and increased confidence in dealing with any future strokes.

Comments suggested that all participants benefited in some way from the information component of the CP. It resulted in a range of perceived changes, including increased awareness of the PWAs' aphasic difficulties and the couple's communication style or

patterns, actual changed communication through new strategies learned, or new strategies for dealing with communication breakdown. These appeared to reduce anxiety about communication and, for some, resulted in perceptions of increased confidence and competence of the PWA. It gave some partners hope for the future and for their relationship. Such findings add to the body of evidence for the benefits to *both* members of a partnership through training partners only (Lesser and Algar, 1995; Booth and Perkins, 1999; Booth and Swabey, 1999). They suggest that the CP can be used cost-effectively for working with partners as co-workers as well as co-clients (see Section 2.5.2).

Despite the majority of participants finding the information useful in some way, for a minority it had some negative effects. In the SP, it appeared to heighten anxiety for one partner (though she implicated her own personality in this). Another suggested information was given at the expense of time for learning practical skills. Another suggested information served to 'punch home' her husband's difficulties and their situation, of which she was already aware but upon which she did not want to dwell. Some suggested that communication strategies suggested were inappropriate or unacceptable. These few negative effects appear to be outweighed by the body of evidence suggesting the benefits of information giving, benefits which have been reported in other partner intervention studies (Bernstein, 1980; Bevington, 1985; Rice et al, 1987; Servaes et al, 1999; Pound et al, 2001). Participants' comments suggested that, overall, receiving information was a valuable component of the programmes. It would seem a central aspect of the learning experience and one which should therefore be retained in future programmes, with obvious close consideration of the potential negative effects outlined herein.

Recording and observing videotapes of conversation both promoted and inhibited participation and change. Several partners found that the videos were able to capture natural every-day conversation and were useful for reflecting on their communication skills, something they had not done before. The process reinforced positive communication and highlighted areas they would like to – and were then able to – change. These findings mirrors that of Hansebo and Kihlgren (2001), who used the process with carers of people with dementia to reflect on their interactions during caring duties.

For some, observing videos resulted in social comparison with a positive outcome. For a minority, however, the process of recording the videos was stressful and/or resulted in unnatural conversation, which therefore negated its usefulness. Observing the tapes in the sessions caused these few embarrassment and/or promoted social comparison with a negative outcome. Armstrong and McGrane (2003), whose recent study replicated the programmes described in this thesis in rural Scotland, found some partnerships reluctant to video themselves, and one partnership to produce a non-representative conversation sample. They improvised by using video clips featured in SPPARC resource pack (Lock et al, 2001), which they found useful. The present study, however, has shown the use of video to be a valuable clinical tool, but one which has the potential to create some distress. Findings suggest that clinicians should be encouraged to use video as a learning resource but prepare participants for its use sensitively and thoroughly.

Role-plays were another organisational imposition, which caused mixed reactions. While just a few partners enjoyed doing them and found they promoted change by increasing their awareness of the PWA's difficulties, others found them objectionable and not representative of real life. Role plays were particularly unpopular with those in TO2, who suggested they were insufficiently prepared for them and that they came at too early a stage in the programme, when they did not know each other well enough not to be embarrassed. Sensitivity is again called for in terms of the introduction and management of such activity.

Factors that appeared to be conducive to both participation and change included the therapist's information-giving style, demeanour and relationship with the participants. Pound et al (2001) also noted the positive influence of the therapist on spouses' group participation. Factors that appeared to inhibit participation to some degree included programme timing, expectations, commitment to so many sessions, difficulties finding care for the PWA while at the sessions, difficulties travelling to the venue (which hindered attendance in Armstrong and McGrane's (2003) study), the number/mix in the group, and the programme/session structure. One of these factors that stood out as important in terms of its influence on change, was timing of the programmes post-stroke. Some suggested that the programmes had come too late for them to change their communication with their PWA as they had learned ways of managing communication in the months or years before they joined the programmes, a finding that concurs with that of Herrmann and Wallesch (1989). However, there was some evidence in the

interview data, and from CA carried out outwith this thesis, that some of these 'ways' of communicating may have been at best ineffective and at worst threatening to the PWA's competence and self-esteem (Lock et al, 2001). However, the PWAs' perspectives and/or conversation analysis data would be required to confirm this. There was also evidence to suggest that those who perceived they had managed without professional support or with minimal information prior to joining the programmes had done so at some cost to their own well-being. Several had felt poorly prepared to cope, fearful and uncertain of their own skills in caring for and communicating with their PWA in both the acute and chronic stages (also noted by Zraick and Boone, 1991 and Pound et al, 2001). These findings highlight the importance of programme timing: if offered earlier they may foster positive strategies for communication and prevent the adoption of those that are potentially face-threatening, and thus psychosocially damaging, for the PWA. Early information and support may also prevent unnecessary psychosocial suffering for the partners and better equip them for coping with living and caring for a PWA. However, the issue of timing is not a straightforward one. The message from (albeit only) one partner (Tina) who had attended a support group early after her husband's stroke was that this had been damaging rather than helpful: she was not ready to hear about the longer term consequences of aphasia and post-stroke disability at that stage. It could be suggested that the programmes were not offered at the appropriate time for the dominant member of TO2 (Vera), whose needs and behaviours had such a deleterious effect on group dynamics, though she perceived them to have been timeous. It was also obvious for a few others – notably the irregular participant (Amy), and the person who withdrew from the project (Gwen) – that though they stated the timing of the programmes had been right for them, factors related to individual circumstances and group and personal processes, prevented them from making the most of the programmes. The findings suggest that more attention to timing of these programmes is needed. Research into the relationship between programme timing, the 'stage' individuals are at in their life and 'career' as a partner and carer of a PWA or in, say, the grief process, and attendance, participation in programmes and psychosocial and communication change, may be particularly useful. However, given the complexities of everyday life and relationships post-stroke, suggested herein and in other studies (eg Pound et al, 2001), it may be that there is never the 'perfect' time for such groups. Offering 'rolling programmes', where people enter and exit as they need or want to, may be an alternative to the programme structure described in this thesis, The resource heaviness of such a programme may make such an option unviable, however.

Finally, regarding the structure of the programmes, Pound et al (2001) implied criticism of the CWC project SP and CP for being ‘prescribed’ in advance of people joining them, rather than being led by what individuals themselves consider important. While Pound et al’s own custom-made programme to suit the needs stated by each individual taking part may be an ideal, like this one, it was not universally successful in bringing about dramatic change for all its participants. Pound et al’s approach is also extremely time- and resource-consuming, meaning busy clinicians may find it impossible to replicate. The findings from the current study did not suggest that participation or outcome were particularly negatively affected by the structure imposed by the programmes being set in advance and personalised as far as possible ‘on line’. As stated earlier, some partners liked and appeared to benefit from the structure, others did not: nobody suggested they had been ‘conscripted’ into following the programmes’ philosophy and there were obvious factors outside of the programmes that influenced the likelihood of change. This may indicate that it is clinically viable to offer ‘set’ programmes, with the understanding that a range of factors, not just those related to programme organisation, are likely to affect outcome. The programmes described herein have now begun to find their way into everyday clinical practice and have been found to be effective (Armstrong and McGrane, 2003; Nieuwenhuis, in press).

5.4.2 Individual circumstances

Individual circumstances outside of the sessions that appeared to affect attendance, participation and change were daily life events and those linked to the partnerships’ relationship. Because few partners contributed comments about these factors, conclusions about them must be tentative. It can be recalled that only Amy attended sessions irregularly. Contributing to this was the business of everyday life: she suggested that she was too busy to come to the sessions. A couple of other participants also suggested they felt a sense of burden from having to fit in the sessions on top of their daily duties. Perhaps more significantly, some saw daily living activities as preventing psychosocial change (such as taking time out for themselves) from being achievable, a finding reported for some participants in Pound et al’s (2001) study. Armstrong and McGrane (2003) found that partners withdrew from their programmes due to personal or family illness or could not accept the offer to join in the first place because of work or family-care commitments. These factors also resulted in withdrawal of partners from the original CWC project. Running programmes out of working hours, as suggested by Armstrong and McGrane (2003), or adapting them to a domiciliary

setting and working with the couple together (which happened as part of the CWC project, see Lock et al, 2001), may alleviate some of these difficulties.

For a small number of participants, the degree to which they involved their PWA in the programmes, and the PWA's reactions to the programmes, appeared to be linked to their relationship and personality factors, and to influence participation and change. For example, one partner's (Carole's) discussion with her husband about her sharing of feelings in the sessions was the first time she had openly acknowledged her feelings to him: an indication that the programme created a change in this aspect of their relationship. She also suggested he had 'improved' because her attendance at the group was a sign of her interest in him, though she suggested his obstinacy had prevented him from accepting suggested communication strategies. For a couple of other partners, pre-stroke relationship difficulties appeared to inhibit the partners' participation and change: they felt their efforts at implementing change were thwarted by their PWA's attitude. Indeed, for one or two, the partners' participation in the programme may also have inflamed certain pre-existing relationship problems. Though the above factors were not probed fully, the evidence herein may suggest that partnerships' pre-stroke relationships may influence outcome, a finding also reached by Pound et al (2001), as may individuals' personality characteristics. It may be that if the PWA is offered the opportunity to 'buy into' the programmes, change may be more likely.

Like Pound et al's (2001) study, this one suggested that some partners' and partnerships' lives were so filled with challenges, changes and difficulties post-stroke, that they were unlikely to be alleviated by the relatively short-term nature of the interventions described. Further research is obviously required to confirm links between pre-stroke relationships, personality types, and communication and psychosocial change through the programmes reported here.

5.4.3 Group and personal processes

Attendance, participation and psychosocial and communicative change were all influenced by a diverse range of factors relating to group and personal processes that occurred in the sessions. Again, some of these were related to all or most participants, and others were evident for just one or two. Perhaps the most striking of these was the drive towards a process of social comparison. Comments from all but one participant suggested they had evaluated themselves or their situations against their fellow group

members, through processes of upwards, downwards and sideways comparison, which promoted a range of reactions.

The process of social comparison within the programmes was obviously a complex one, which worked in different ways for different individuals. Contemporary knowledge of social comparison theory (see Suls and Wills, 1991 for full review) can be used to explore this complexity. One's self-concept (ie, what we know about ourselves) is shaped in part by comparisons of our selves with others. The process of sideways comparison occurs when we seek out similar others against whom we can accurately evaluate ourselves and learn about our personal qualities: healthy self-esteem is dependent on favourable comparisons (Festinger, 1954 in Smith and Mackie, 2000). In the current study, sideways comparison had a positive outcome. It enabled participants to recognise similarities with other group members, normalise and validate their thoughts, emotions and experiences, and gain support.

Previous research has suggested that upwards comparison (ie comparisons with others considered more fortunate) is used to gain information and affiliation (Taylor and Lobel, 1989). This did not appear to be the case in the current study. Though the process may have created aspiration in one participant to develop a more positive relationship with her partner, for others it resulted in feeling negative about their own situations. For one person in particular (Gwen), it challenged the coping strategy she had developed for managing life with aphasia and contributed to her departure from the programme.

Downwards comparison (comparisons with those considered less fortunate) has been found to be used for different purposes and with different outcomes. For example, it has been shown to be used to make explicit self-evaluations (Taylor and Lobel, 1989). In a study of people with learning disability, Finlay and Lyons (2000) suggested that downwards comparisons served to maintain a positive sense of self and social category. Osborn and Smith's (1998) study of people with chronic back pain suggested a more negative result of the process: an increase in fear of the future and feelings of uncertainty. The current study showed the process to create positive, negative and mixed outcomes. Although all partners who embarked on the process emerged from it feeling more positive about their own situations, there were different effects of this. For example, one person was able to use that positiveness to facilitate another group

member's participation in the programme; another felt discomfort at thinking about those worse off than her yet used the process as a spur for moving forward with her life.

The findings in this study suggest that the process of social comparison was a central feature of participation in the programmes, which created a range of reactions. Positive effects included the recognition of shared experiences and feelings, normalisation, validation, new ideas for coping and new friendships. It made several feel more positive about their own situation: for example it created hope for their relationship, a sense of gratefulness, empathy towards other group members and a drive to make positive lifestyle changes. Less favourable effects for some participants included negative feelings about their own situation and the recognition of and challenge to their personal response to their situation, which was neither comfortable nor desired at the time. This study appears to confirm the complexity of social comparison theory and has added to the literature about ways in which social comparison is used.

The suggestion that social comparison influenced both personal processes and experiences of the groups may have important implications for planning future groups and research. It could be suggested that attempts should be made to avoid the negative effects of social comparison, for example, by ensuring that there is never an 'outlier' in the group, such as a partner with a PWA with significantly worse problems than others, or a sole male, or a sole non-spousal relative. However, finding 'matches' for participants in both research and clinical practice may be difficult – it was impossible for the CWC Project - and it is probably a *fait accompli* that there will always be somebody in a group whose psychosocial life has been more severely or differently affected than others. It may be apposite, therefore, to ensure that participants are prepared for the process of comparison and its potential outcomes prior to joining a group. This preparation could form part of a pre-programme information package. Programme facilitators must expect and be prepared for social comparison to occur, and be watchful for the processes it promotes: it should not be assumed that people are always 'helped up' by each other and will not experience some negative effects of comparison. Research with therapy groups of the kind reported here should keep abreast of developments in social comparison theory.

'Sharing', or the process of exchanging thoughts, feelings and experiences, was the second theme related to group and personal processes. Sharing facilitated participation

by promoting discussion of personal feelings, ideas and experiences. This in turn promoted change by enabling participants to learn new ideas and skills for coping and communicating, increasing their awareness of and relationships with others in the sessions, and reducing their sense of isolation. For some it created hope for or actual lifestyle changes for both the participant and their PWA. This dual benefit was an aim of the CWC project (Lock et al, 2001) and again highlights the potential of such programmes as a cost-effective means of service delivery. There was no suggestion that sharing inhibited change for anybody, though it was a factor in one participant's (Amy's) irregular attendance.

This sense of 'sharing' has been a much-reported benefit of group work in general (Bender, Norris and Baukham, 1987; Walsh, 1993). Participants in Pound et al's (2001) study and in Armstrong and McGrane's (2003) study commented on the advantages of sharing experiences and learning from others. However, no other studies of SLT-based programmes for partners have addressed the effects of sharing in the detail that this thesis has. The findings herein suggest that, like social comparison, sharing was a central aspect of participation in the sessions. Several gained emotional support from the process, which, as stated in Section 2.4.8, has been found to be the most useful type of support for coping with life stressors (Sarafino, 1994; Wills, 1997). The predominantly positive effect of sharing implies that future programmes should encourage sharing by incorporating plenty of opportunities for doing so into each session, perhaps to a greater degree than was provided in the SP and CP reported herein.

The final main factor related to group and personal processes and which affected attendance, participation and change, stemmed from the needs and behaviours of a dominant group member. It can be recalled that Vera dominated the sessions with monologues about both her experience of her husband's stroke and her relationship with him. Other participants saw her as more needy than they were, but while some were able to accommodate this, some found her dominance tiresome. Gwen strongly implicated Vera's behaviour in her departure from the programmes. Group work theory describes Vera as a 'habitual monopolist', considered by Yalom (1975) to be possibly the greatest challenge in group work. While the appearance of such a person in groups is not a given – there was only one in the CWC project – their marked effect on other individuals and on group dynamics warrant consideration when planning programmes. It could be suggested that the SP and CP were not the most appropriate form of

intervention for Vera at the time of the CWC project, and that, say, individual counselling may have both addressed Vera's needs more effectively and avoided the consequences for the rest of the participants. However, Vera's own interview comments suggested she perceived many benefits of the programmes, which may imply that clinicians have an ethical duty to enable people with such complex needs to participate in them. Several options for dealing with this could be considered, including better management of the dominant member within sessions (Bender et al, 1987; Finlay, 1993). My own feelings are that somebody with greater counselling or group work experience than me may have had more effective strategies for managing Vera. This may indicate that programmes such as those described in this thesis could benefit from being co-run by a professional with such experience. However, given current levels of staffing and funding, such an option may be impossible.

Bender et al (1987) points out that there is no simple way of dealing with a dominant or disruptive group member, because there is no simple 'cause' for the disruption: disruptive behaviours may stem from a myriad of complex and difficult psychosocial issues. This certainly appeared to be the case for Vera, and implies that uncovering the *potential* for disruptive behaviours prior to a person's acceptance onto a programme may enable decisions to be reached about candidacy for positive participation and change. A pre-programme interview may be able to address this, but further research about candidacy for programmes is obviously required.

5.4.4 Interaction of factors affecting attendance, participation and change

Participants' perspectives on the factors influencing their participation in the SP and CP and psychosocial change suggest wide variability in the mechanisms at work for each person and in the effects of the programmes. Each person appeared to react differently to different combinations and interactions of factors related to the content and organisation of the programmes, personal circumstances outside of the sessions, and group and personal processes within them. Appendix 2J summarises thematically the variety of factors that promoted and/or inhibited participation and change. There were no distinct overall patterns of participation or change, suggesting that evaluating whether the programmes were 'effective' or not, or tracking a positive indicator for successful group work for partners, is not straightforward. It can be recalled from Study One that the PQRST results suggested that only half of all participants reaped

psychosocial benefits of the programmes. The findings in the current study suggest that all benefited psychosocially or in communication with their PWA in some ways, though some appeared to get more out of the programmes than others, and some also could be seen to experience some level of distress as a result of their participation. Appendix 2K summarises the psychosocial and communication-related changes described by each participant as a result of the SP and CP.

Perhaps the most striking illustrations of the complexity of the relationship between factors identified are those that influenced irregular attendance by Amy and withdrawal from the CWC project by Gwen. For Amy, these included being busy with everyday life, anxiety about leaving her husband alone, the programmes not meeting her expectations and uncomfortably challenging her way of coping with her husbands' difficulties and resulting psychosocial changes, and the behaviours of other group members. It was suggested that this participant appeared to use the process of social comparison during the sessions she did attend to drive her towards more positive psychosocial action for her and her husband. This could imply that her non-attendance indicated a positive outcome, and may therefore challenge clinical presuppositions about the negativity of clients' withdrawal from such interventions. For Gwen, on the other hand, her withdrawal from the programmes appeared to be the consequence of an interaction of 'depression' from the recognition, via social comparison, that her husband was worse off than others, the programme upsetting her coping strategies, and the behaviour of the dominant group member. Again these findings suggest that clinicians need to be cognisant of a host of potential interacting factors that may influence a participants' decision to withdraw from programmes, and attempt to recognise and deal with these timeously to avoid unnecessary distress. Running programmes with a co-worker (perhaps an experienced SLT assistant) who could monitor individual reactions and group dynamics, or at least videotaping sessions, may address this issue. This may be a useful area for future research.

5.4.5 Critique of the study

This section critically evaluates the study, its methodology and its trustworthiness. It considers whether the methodology is appropriate for research and clinical practice.

The sample

The small sample size of 11 participants in this study, and therefore the need for research with larger, purposively sampled groups, is acknowledged. Despite the limitations of the small sample, it nonetheless provided considerable insights into a range of themes and individual partners' perceptions, needs and experiences related to the programmes being evaluated. The information they provided may be valuable in shaping the development of future programmes and at least indicate areas that require further consideration or research. It is acknowledged that the findings from this sample were 'one-sided', that is, the perspectives of the participants' aphasic partners were not sought. The omission of the PWAs' perspectives from this thesis is justified because partners experiences and needs are worthy of attention in their own right. However, the inclusion of the PWAs' perspectives in future studies of this nature may provide greater and different insights than have been possible to achieve through the partners' alone.

The interviews and the interviewer

The method of this study involved a research participant, Lauren, interviewing fellow participants about their experiences. Prior to the interviews I was concerned that Lauren's own experiences as a partner of a PWA, of attending the programmes and her relationship with fellow participants would unduly influence the direction of the interviews and the responses of the interviewees. I was also concerned that her own interpretations of the data would influence me to the extent that I would not be able to see beyond her interpretations to what actually lay in the data itself. To address these concerns, Lauren's own disclosures and evaluations during the interviews were recorded in the findings, thus providing a level of transparency from which her own perspective and influence could be examined. These actions were considered a requirement of trustworthy research. It was seen that Lauren did not appear to have overly-shaped participants' responses, but where she did, her contributions were included in the data provided. Lauren's own disclosures were often a catalyst for further discussion or revelation by the interviewees, a finding that can be allied to the positive effect of helper self-disclosure during counselling and self-help groups (Peca-Baker and Friedlander, 1989). While it is acknowledged that self-disclosure during counselling can disturb clients (see, for example, Derlega, Lovell and Chaikin, 1976), this did not appear to be the case in the interviews for this study. Though seeking participants' feedback about the process of their interview with Lauren may have provided greater insight into the appropriateness of her role, the data she was able to gather for the study suggests that

using a research participant in this way was useful. However, the interview data were not flawless. They did capture partners' perspectives on various factors that influenced attendance, participation and change, but it was evident that some themes identified were contributed to by only one or a few participants. This provided a good deal of information about idiosyncrasies, but little about representative patterns from which generalisations may be more likely: just because some partners did not discuss some issues does not necessarily imply that they were not important to them. It was also evident from the transcripts that some issues raised in the interviews were not fully probed. This implies that conclusions from the study should only be tentative, and has resulted in a sense of incompleteness of some of the data, particularly in regard to psychosocial change. Interviewees predominantly spoke of change in relation to aspects of the programme, that is, the nature of their psychosocial lives and experiences pre- and post-stroke and before the programmes were not explored fully in their own right. The interviews certainly did not seek to confirm or deny the existence of the psychosocial and communication issues that partners included on their PQRST assessments described in S1, which can be considered an opportunity missed for S2 to address further some of the weaknesses of S1. However, they exposed some communication and psychosocial-related change for *all* participants that could not be identified using the erstwhile primarily quantitative method.

The above-mentioned flaws are likely to stem from a combination of the interview topic guide being focused predominantly on the content and organisation of the programmes, and the interviewer not probing in sufficient depth. It is possible that a broader topic guide and an interviewer who was further removed from the programmes, or who had a wider remit, would have provided richer and more detailed data which would have led to more concrete findings. However, I would argue that the ideology behind using a research participant as co-researcher, who has experience of living with a PWA and of the programmes being evaluated, is worthwhile for getting close to and uncovering the perspectives of the people being researched. It indicates attention to reflexive research practice (Smith, 1994), discussed in Section 4.3.1. Perhaps with certain alterations to the interview design, such practice could reap greater rewards for future studies.

The analysis method

Data was analysed following the Framework Method (Ritchie and Spencer, 1994), with the rationale that it was an established qualitative research method with a track record in

studies of insider perspectives, and because it provided a systematic charting system suited to multiple data sets and for exploring emerging themes. My method of data analysis – fully explained in the findings section – was indeed systematic and involved meticulous sifting through and reduction of the data. This led to findings that were grounded in the data and demonstrated attention to rigour (Smith and Osborn, 2003), a concept introduced in Section 4.3.3. It also illuminated what appears to be the essential essence of participating in a support and conversation training programme, as defined by the participants themselves. The design was able to accommodate the range of individuals' experiences and elicit several salient issues. This is consonant with the view of the contribution of qualitative research, as expressed in Chapter 4.

The analysis process culminated in a series of charts, designed to enable full exploration of the variety and range of data within and between participants. During this exploration I found myself constantly referring to original transcripts to double-check my analysis and interpretations on the charts. While a more experienced researcher may not feel the need to use such a 'safety net', and while a positive aspect of FM is that its transparency allows this forward and backward referral through stages, the whole process was enormously labour- and time-intensive. Time for such a level of analysis is perhaps a luxury of research, but not one enjoyed by busy clinicians. This factor alone may make such a method of programme evaluation unsuited to clinical practice, unless it can be 'tamed' in some way. In terms of its applicability for research, however, the method appeared to suit the variability of the data available in this study: it enabled a certain degree of 'quantification' of the data in terms of numbers of participants contributing to themes. This was considered important given the requirement to provide a transparent view of how thematic findings were reached, and how representative they were of the sample. It also allowed individual perspectives to be tracked, though the nature of the data meant that a complete picture of individuals' experiences was not possible. This is more likely to have been a result of the data collection process than the analysis method. It can be concluded that FM was a valuable research tool for this study.

Positivists may suggest that a quantitative research design, larger sample size and standardised measurement would have enabled the findings to be generalised to other people or situations, which is not possible through qualitative methodology. However, given the complexities of organising the programmes featured herein, the wide variations in and interactions between factors that influenced individuals' participation

and change, it is doubtful that quantitative methods could capture these, as has already been found in previous research and discussed in Chapter 4. Also, individual variations in experiences and the differences in outcomes which seem bound to occur as a result of interactions between programme organisation, individual circumstances and personal and group processes, imply that evaluation of partners' experiences of such interventions should be personalised and on-going, from programme to programme. In the clinical setting, then, there is a requirement to balance the need to use a method that provides insight into individuals' needs and meaningful service evaluation, with the constraints of time and methodological demands. Most clinicians will not have the time or knowledge to use the methods employed in this study, and their employers may not have the budget to train or employ a researcher specifically to undertake qualitative interviewing and analysis, as proposed by Pound et al (2001). An alternative may be to design a comprehensive yet time-efficient assessment and evaluation package, which incorporates both qualitative and quantitative methodologies, based on the findings of this thesis.

Trustworthiness of the study

The use of FM is still relatively new in aphasiology, though practical guidelines and published studies using this approach do exist (Ritchie and Spencer, 1994). As noted in Section 4.2.1, previous qualitative studies within aphasiology have not addressed researcher bias or issues of reflexivity, which are considered important criteria of trustworthiness in qualitative research featuring data interpretation. I have addressed this issue throughout the study, by including personal details and 'owning my perspective' (Elliott et al, 1999), and also by explicitly describing that of the interviewer. It is hoped that this action enabled the reader to understand how and why the findings were reached and has addressed criticisms of previous research using FM.

Participant reflexivity was also addressed in the study. It was suggested in Section 4.3.1 that 'better' data arises from more articulate and reflective informants (Miles and Huberman, 1994). In this study, it certainly appeared to be the case that those who subjectively appeared more articulate and reflective offered some important insights into their experiences. However, I attempted to represent the perspectives of all participants, which is evident in the broad cross-section of verbatim extracts provided.

Another aspect of trustworthiness, described in Section 4.3.2, is sensitivity (Henwood and Pidgeon, 1992; Yardley, 2000; Smith and Osborn, 2003). This study demonstrated sensitivity to the data and 'importance of fit' by grounding analysis in the data and supporting findings and interpretations with verbatim evidence from the participants themselves. Related to the issue of sensitivity was my concern that the interviewer's and my own knowledge of and 'closeness' to the participants and programmes they were evaluating would lead them to feel obliged to answer all questions positively (ie the risk of acquiescence). I was also concerned that my desire to see a successful outcome would - not necessarily consciously – cause me to interpret and present findings with a positive skew. To address this, I made every attempt to report negative as well as positive findings, again supported by verbatim evidence. It is hoped that the range of opinion provided by participants and in the study supports the research findings as trustworthy. That participants on the whole did not appear to acquiesce may be a result of different factors, including:

- the interviewer's encouragement to them to be as open and honest as possible in their feedback of the programmes, and giving them a rationale for this;
- the analysis process which promoted structured charting of *all* responses to a theme;
- the continuous auditing of the analysis process by a third party to ensure an adequate level of quality control.

The study's attention to rigour was illustrated earlier in relation to the thoroughness of the analysis. I also demonstrated this through the independent audit process and 'credibility checks' (Miles and Huberman, 1994; Elliott et al, 1999) made throughout different stages of the study. Again, this was made possible by providing an explicit and transparent outline of the research process (Huberman, 1994; Smith, 1996), another factor indicating trustworthiness of the study (Henwood and Pidgeon, 1992; Elliott et al, 1999).

Impact and importance

Section 4.3.4 introduced the relationship between a study's impact and importance and its 'transferability', 'fittingness', 'utilization' or 'application', and the degree to which the research fulfils its goals. In terms of the transferability and application of this study, it has already been acknowledged that a small selection of partners were interviewed,

the majority of whom were female spouses living with a person with predominantly expressive language difficulties. Data from more male partners, those living with people with more severe or primarily receptive problems, those who are carers but not spouses are not fully represented. Before assessing whether the findings of this study are applicable to such groups, it would be important to access their perspectives. The study is, however, utilisable. It has provided evidence for a range of factors influencing programme participation and psychosocial and conversation change which can be used clinically to inform future programme development. It has challenged some clinical presuppositions and has begun to provide a 'theory of therapy' for the programmes described, has contributed new insights for established theories, such as that for social comparison, and has raised issues which need to be considered in further research.

5.5 Study conclusions

This study aimed to identify and present insider perspectives on the factors influencing participation in and change through a support programme and a conversation training programme for partners of people with aphasia. The following main conclusions can be drawn:

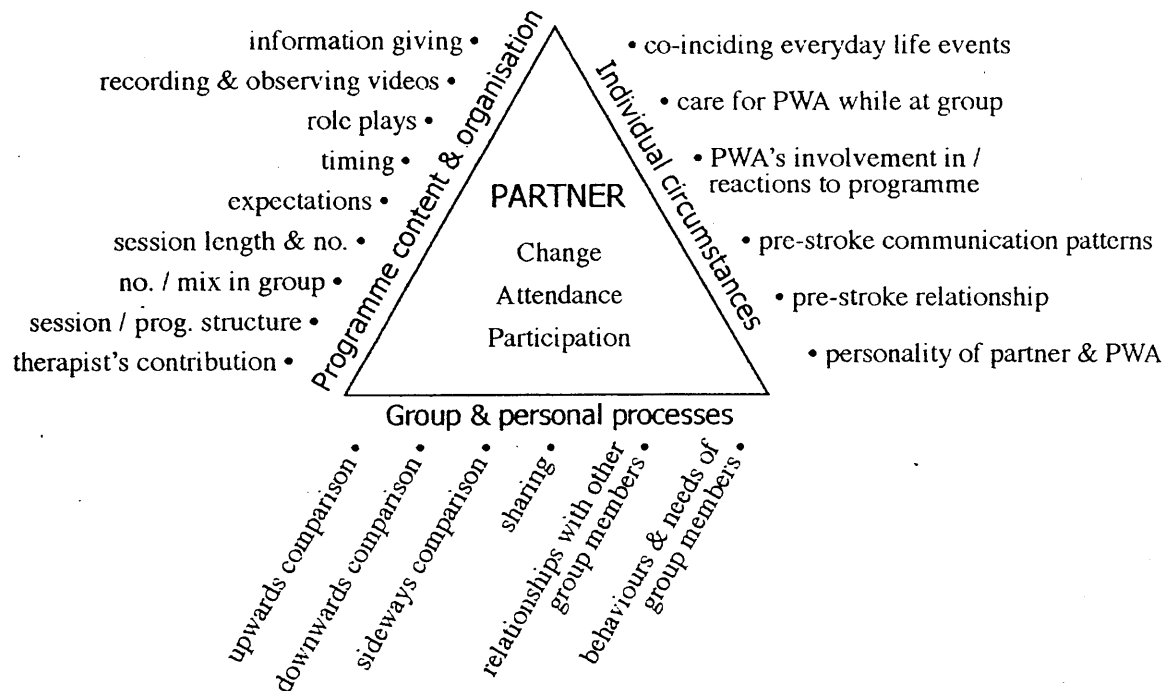
- 1 Participants' reports suggested that factors within the domains of
 - i) the content and organisation of the programmes,
 - ii) individuals' personal circumstances,
 - iii) group and personal processes,operated to influence their attendance at and participation in the programmes, and communicative and psychosocial change.
- 2 Different factors interacted with each other to shape people's experiences of the programmes and outcomes. Nobody's experience or outcome was the same. However, all 11 participants found both the Support Programme and Conversation Programme useful in some way. Certain aspects of the programmes caused some distress.
- 3 In uncovering the processes behind outcome the present study goes some way towards a 'theory of therapy' for the programmes, and provides a three-stranded

frame of reference which is utilisable as a clinical checklist for planning, facilitating and evaluating future similar interventions. This frame of reference, summarised in Figure 2.1 below, is partner-centred: the study findings were derived from the perspectives of the partners themselves and therefore reached in a level of partnership with them. It located the partners within an organic, multi-party system that incorporates the PWA and partnerships' individual circumstances, alongside those related to service provision practicalities and the known effects of group work.

- 4 Related to this, clinical objectives of partner participation in and change through such programmes should be seen as fluid, and subject to variations in individuals and influencing factors over time and situations.
- 5 The qualitative Framework Method utilised for this study enabled findings to be reported for individuals within broad themes, and allowed both outcomes and process to be identified. This had not been possible through the quantitative measure used in Study One. It can therefore be considered a valuable resource for programme evaluation research.
- 6 The study pointed to the need for further intervention research in several areas. These include:
 - i) the nature of the interactions between factors that influence programme participation and change;
 - ii) the influence that factors such as individual personality type, coping strategies and partnerships' pre- and post-stroke experiences and relationship have on candidacy for change;
 - iii) the effectiveness of running programmes with a co-worker;
 - iv) programmes for more homogeneous groups of participants, including male spouses, non-spousal partners, those living with PWA with similar linguistic abilities.
- 7 The primary focus of the interviews and subsequent data analysis were on broad themes related to the programmes. This resulted in an incomplete understanding of the psychosocial experiences of each individual outside of the context of intervention. There remained a need to research in greater depth individuals'

perspectives on their experiences of living with and caring for a PWA in their own right. This was intended to provide a deeper understanding of partners' lives post-stroke, upon which future interventions could be developed. It is suggested that a qualitative method capable of capturing and exploring individuals' meanings to a greater degree than the interviews and theme-based FM analysis of S2 would be required for such research. This single case approach is the focus of the final study of this thesis.

Figure 2.1: Factors that may influence attendance, participation and change in the Support and Conversation Programmes: a clinical frame of reference



CHAPTER 6

STUDY THREE

**Rescue, endurance, regeneration:
the phases of a partner's
caring and coping experience.**

An interpretative phenomenological analysis

Introduction

The third and final study of the thesis is an in-depth case study of one woman's experience of living with and caring for her husband, a stroke survivor with aphasia. The study is from the partners' perspective: her experiences were recounted during an in-depth, semi-structured interview and the data was analysed using Interpretative Phenomenological Analysis (IPA) (Smith, 1995; 1996). Chapter 1 situates the study within the thesis as a whole, though the background, rationale and aims of the study are discussed more fully in the following section.

6.1 Background, rationale and aims of the study

Existing literature and this thesis so far points to a strong case for undertaking research which attempts to uncover and understand the psychosocial needs and experiences of partners and carers of stroke survivors and PWA (eg Quereshi and Walker, 1989; Anderson, 1992; Addington-Hall et al, 1998; Ellis-Hill, 2001). As noted earlier, most psychosocial research in this field to date has been carried out from the researcher's perspective, using primarily quantitative methods (eg Wade et al, 1986; Christensen and Anderson, 1989; Herrmann and Wallesch, 1989; Dennis et al, 1998; Zraick and Boone, 1991). These have therefore been unable to fully expose, explore or explicate the range and complexities of partners' needs and experiences resulting from their relative's stroke. Though idiographic, Study One of this thesis could be described as such. It was noted in Chapter 4.2 that in recent times a few studies have been carried out from the partners' perspective. These have used qualitative methods of data collection and analysis to more effectively uncover and describe psychosocial changes for partners (eg Le Dorze and Brassard, 1995; Ellis-Hill, 2001; Pound et al, 2001, Hunt and Smith, 2004). Such studies have presented findings in terms of themes across small samples, and have therefore provided a *broad* sense of partners' experiences. Study Two of this thesis is such a study: it was carried out from the partners' perspectives, and its methodology meant that it was able to contribute to the body of 'insider knowledge'. However, its findings were predominantly about partners' experiences of participating in intervention. The more fundamental question of what it is *really* like to live as a partner of a PWA was left tantalisingly unanswered. If professionals are to provide interventions which are as meaningful as possible to partners themselves, they first require a deeper understanding of partners' perspectives on their psychosocial

experiences. Further research, using a method designed specifically to capture individuals' meanings in greater depth, and thus overcome the shortcomings of previous studies, is therefore called for. The current study aims to address that need. It asks the question: **how does a partner perceive and describe her experience of living with a person with aphasia?** The question is explicitly broad to allow the participant to lead the discovery process. To achieve the study's aim, a research method that is particularly suited to the task of capturing complex and subjective matter from a holistic perspective, which the methods used so far in this thesis have not been able to achieve, has been chosen. This method is IPA, which is now described and placed within the broader qualitative paradigm introduced in Chapter 4. The remainder of the chapter details the method and procedures for this particular study, and presents and discusses the findings.

6.1.1 IPA

Both the research question of this study and IPA (Smith, 1995; 1996), the method used to explore it, reflect an inductive, interpretative qualitative epistemology, as befits the investigation of complex issues that have been only partially addressed by previous research studies. They embrace the basic tenets of the 'constructivist-interpretative' paradigm, based on a relativist ontology (ie there are multiple realities), a subjectivist epistemology (knower and subject create understandings), and a naturalistic (in the natural world) set of methodological procedures (Denzin, 1994). The paucity of prior research in the area related to this study made the choice of an inductive epistemology vital. It emphasises the 'discovery dimension' that underlies the development of hypotheses, rather than the empirical confirmation or disconfirmation of already-established hypotheses. It therefore allows unexplored domains to be mapped, initial questions to be refined and changed, and theory to be generated and reworked (Henwood and Pidgeon, 1992; Guba and Lincoln, 1994). This discovery dimension is a feature of phenomenology, which emphasises 'going back to the things themselves' and which is committed to a psychological focus and a concern with the direct study and description of the subjective lived experience (Giorgi, 1985, 1992; Giorgi and Giorgi, 2003). IPA is phenomenological. Developed by social psychologist Jonathan Smith and his colleagues (Smith, 1995; Smith, Harre and Van Langenhove, 1995; Smith, Flowers and Osborn, 1997; Smith, Jarman and Osborn, 1999), IPA's goal is to 'explore in detail the participant's view of the topic under investigation' (Smith et al, 1999, p218).

Why IPA? Unlike the Framework method (FM) of analysis used for Study Two, which has not been explicitly placed within a theoretical position by its devisers, IPA's position is well documented. IPA is an idiographic (employing purposive sampling and case analysis), inductive, process-oriented approach with connections to phenomenology, social cognition and symbolic interactionism. It is phenomenological in that it is concerned with an individual's personal perception or account of an event or experience, rather than attempting to produce an objective statement of the event or experience itself (Smith et al, 1999). IPA's link with symbolic interactionism is that it recognises that the meanings individuals ascribe to events can only be obtained through a process of interpretation (Smith et al, 1990; Smith, 1996). In other words, 'even though IPA aims to explore the research participants' experience from his or her perspective, it recognises that such an exploration must necessarily implicate the researcher's own view of the world as well as the nature of the interaction between researcher and participant' (Willig, 2001, p53). In other words, meanings are negotiated within a social context (Smith, 1995). This is something that analytical approaches that are 'closest' to IPA, such as phenomenology, Grounded Theory and even FM, do not necessarily consider. Hence, rather than leaving analysis at the descriptive level of phenomenology (Giorgi, 1992), IPA adds an interpretative component. This is considered a fundamental necessity for understanding what a person thinks or believes about a topic, ie his or her cognitions, because these are considered not necessarily transparently available from, for example, interview transcripts (Smith, 1996; Smith et al, 1999).

Though Hunt and Smith (2004) recently used IPA to study the experiences of four partners of stroke survivors of six months or less post-onset, IPA has yet to be used within aphasiology or for the study of the long-term experiences of partners of PWA. It has, however, been widely applied within health psychology research and to the study of such diverse individual experiences as hearing voices (Knudson, 2002), chronic back pain (Osborn and Smith, 1998), anorexia nervosa (Jarman, Smith and Walsh, 1997) and genetic testing (Smith, Stephenson and Quarrel, 2000). IPA's exclusive concern with psychological phenomena, subjective experience and interpretations make it particularly appropriate to the study of psychological questions, and therefore to Study Three of this thesis. This is in contrast to Grounded Theory, for example, which emerges from a sociological context (Strauss and Corbin, 1994; 1998). It is also in contrast to FM (Ritchie and Spencer, 1994), with its roots in social policy research and a set of

procedures that are more applicable to cross-case analyses than to in depth exploration of individuals. In other words, IPA seems to offer a method of gathering rich accounts of individuals' perceptions and conceptualisations of their experiences, which focuses on personal meaning (rather than sociological constructions). It enables interpretative elaboration of that meaning – even to the degree of connecting it to extant theoretical concepts – without losing contact with the original experience or its context.

Most IPA studies have utilised semi-structured, in-depth interviews; the characteristics and benefits of which have already been described in Chapter 4. This data collection method was chosen for the present study because it strikes a balance between specifically addressing the research question and leaving enough open-ended space for the establishment and exploration of new, possibly more relevant questions during the interview process or elaboration of themes introduced by the participant. The analytic procedures of IPA are well-documented (Smith et al, 1999). The first stage should entail multiple readings of a transcript with an open mind, where 'each reading has the potential to throw up new insights' (Smith and Osborn, 2003), and noting what is interesting or striking about the text, as well as themes that seem to emerge from the account. The initial process of generating emergent themes is followed by the second stage, 'clustering of themes' (Willig, 2001), which involves exploring the relationships between the themes, and seeing where it makes sense to cluster them into thematically related groups. This begins to produce superordinate categories with varying numbers and layers of subordinate themes. Throughout the process, the emergent thematic clusters are checked continuously with their original sources in the transcript, to 'make sure the connections work for the primary source material' (Smith and Osborn, 2003, p71). Ultimately a final table of superordinate themes is established, from which the next stages of analysis ensue. The shift from pure thematic development to the written account involves articulating the themes in a written narrative that continues to be well grounded in illustrative material from the participant's text, and thus creating transparency and allowing judgement of sensitivity to the data. Smith and Osborn (2003) note that the division between analysis and writing up is, to a certain extent, a false one, in that analysis will be expanded during the writing phase.

My adaptation of the above procedure of analysis for Study Three, a reflection on my interpretative position, and my attention to rigour in the study, are all outlined below.

6.2 Method: details and procedures

This section provides details of the study participant, ethical considerations, and outlines the procedures of data collection and analysis.

6.2.1 The participant and ethical considerations

This study features one participant. The rationale behind including her as a single case was that her data was considered by the thesis supervisors to be so rich and compelling that it lent itself to a comprehensive, in-depth analysis of her experience. In a reflection of IPA's development to date, Smith (2004) highlights the significant value of a detailed single case study, particularly when a case is rich or compelling. As well as enabling a great deal about an individual to be learnt, connections between different aspects of the respondent's account can be seen. Perhaps more profoundly, 'delving deeper into the particular also takes us closer to the universal... to significant aspects of a shared humanity, and the particular case can therefore be described as containing an 'essence'' (p42).

The criteria for joining the study was that the participant should be:

- a female partner, living with PWA prior to and after stroke (thus chosen to reflect the fact that most carers are female, and that spouses have been considered to suffer greater psychosocial distress than other care-givers)
- white British (to reflect the population studied in the thesis as a whole)
- 60 years of age or less (to enable access to a participant who may be working and thus to wide-reaching psychosocial dimensions)

Some criteria were set for the partner's PWA, as follows:

- PWA's stroke must have occurred between 2 and 5 years ago (to ensure that findings reflect chronic rather than acute issues)
- the stroke must have resulted in aphasia
- PWA may have concurrent physical impairments

The participant and her PWA met all of the above criteria. 'Saskia' (a pseudonym) was 58 and had been married to 'Jim' for 39 years at the time of the study. Saskia was a full-time civil servant and Jim was a motor technician at the time of his stroke, which was 3.2 years prior to the study. The couple had two grown sons who lived nearby. Jim's stroke left him with aphasia and a right-sided hemiparesis. His aphasia was not formally

assessed for this study, though Saskia's general perception of his language was accessed at the beginning of the study using the Aphasia Disability Questionnaire from a draft of the Comprehensive Aphasia Test (Swinburn et al, in preparation). This is provided in Appendix 3A. Based on a ten-minute social discussion with Jim at the couple's home prior to the study, my observation of his speech and language was that he was able to understand and respond to context-laden questions in the social setting. He made good use of minimal turns and non-verbal communication, though his expression was marked by moderate- to severe word finding difficulties, and some phonemic and semantic paraphasias. He was in a wheelchair.

Ethical permission for the study was received from UCL. Saskia was referred to the study by the organiser of a local stroke support organisation, who provided her with initial information about the study. This was followed by a telephone discussion between me and Saskia, and Saskia receiving both verbal and written information explaining the nature of study. This outlined the process of the interview, tape recording, what would happen to the data, who would see it and potential outcomes. This was followed by an initial meeting, at which the study process was discussed in detail, and Saskia was given the opportunity to ask further questions. Saskia agreed to take part and asked to be interviewed at home. She signed a volunteer consent form, which formally gave her the opportunity to withdraw from the study at any time. She was offered the opportunity to receive and comment on the interview transcript and analysis, but declined.

6.2.2 Data collection: the interview

My interview with Saskia, when Jim was not at home, was preceded by a discussion during which the aim of the study was reiterated. The interview was tape-recorded. It lasted 110 minutes. A topic guide was prepared for the interview, covering three broad areas:

- i) personal circumstances
- ii) roles, relationships and identity
- iii) coping.

Each area comprised a series of open questions and more closed prompts for use if necessary. The topic guide, which forms Appendix 3B, was informed by the findings and areas identified for further research in Study Two, by knowledge of theory not fully

applied to previous studies in this thesis (eg, of coping), and by writings and recommendations of previous IPA research interviews of personal experience, most notably of Smith (1995; 1996).

The topic guide was not strictly adhered to, but rather acted as a rudder by which to steer the discussion: Saskia was encouraged to raise and explore issues of her own choosing that she felt were important to her. I attempted to probe these in depth where appropriate, though it was obvious in the interview that Saskia needed little help in recalling and describing her experiences or in accessing her thoughts and feelings about them.

6.2.3 Owning my perspective

The reader is referred to Section 5.2.1 of Study Two for a description and exploration of my own perspective as a researcher and SLT, and on my knowledge of psychosocial issues for PWA and partners. I acknowledge that my perspective changed somewhat through the process of carrying out Study Two, in that I felt I had increased, though still limited, insight into the needs and experiences of a particular set of partners and carers of PWA. I took that knowledge, from which I felt I had developed an increased sense of empathy, to my interview with Saskia. Hence, in the interview itself I sometimes felt torn between the requirement to probe or persist with a topic in an attempt to capture Saskia's meanings more fully, and my desire to treat her gently and to help her to feel better when she became upset or distressed. I see this as both an inevitable result of a therapist becoming a researcher, and as a natural reaction to hearing Saskia's intimate human story face-to-face. Despite that, I retained throughout the interview and analysis process a hunger to uncover Saskia's own 'real', lived experience, something that the data from the previous studies had precluded. As with Study Two, an audit of my analysis was built into this study, one reason for which was to ensure my own perspective was considered. The audit process is described in the following section. It is hoped, however, that the above declaration will facilitate reading of the findings.

6.2.4 Data analysis

Data analysis broadly followed the guidelines set out in the IPA literature, most notably Smith et al (1999), though analysis was adapted to suit the data that emerged. The process followed a series of interconnected stages, now described.

Transcription

The interview was transcribed verbatim onto a word-processor document, by me, on the day of the interview. All references to names and places were anonymised.

Transcription followed IPA guidelines (Smith et al, 1999). It was less fine-grained than for Study Two: each turn was preceded by a turn number and the initial of the speaker (I=interviewer; S=Saskia). Stressed words were underscored and non-verbal behaviour (eg crying, sighs) was noted. Spaces were left in the left- and right-hand margins of the document for comments, data descriptions and emerging themes to be noted. Appendix 3C provides an extract from the interview transcript. For details of notation symbols see Appendix 2C.

The audit process was introduced at this early stage. The transcript was sent to the thesis's second supervisor (who was IPA's founder and the primary supervisor for this study) for his initial feedback on the interview as a whole. His comments were that Saskia had provided a rich and insightful account of her experience. He noticed, as I had, that Saskia had provided this account with minimal direction or prompting.

Looking for themes

The transcript was read closely a number of times in order to become intimate with Saskia's account. With each reading, notes were made in the left-hand margin about anything that struck as interesting or significant. Identifying or summarising labels and some preliminary interpretations were also ascribed to text at this stage. Once preliminary notes had been made, key words that appeared to capture the essential quality of what was in the text, ie emerging or potential theme titles, were noted in the right hand margin. These early analytical processes can be seen on Appendix 3C. As suggested in the IPA guidelines (Smith et al, 1999), at this stage, the entire transcript was treated as potential data and no attempt was made to omit or select particular passages for special attention.

Looking for connections

The next phase involved listing the themes that emerged from the initial readings of the transcript and looking for connections between them. This was enabled by the drawing up of a preliminary table, which featured the early themes, the page and turn numbers at which they occurred, and early/potential titles of master themes that appeared to encapsulate them. This is shown in Appendix 3D. At this stage, Saskia's telling of her

experience as an unfolding story that moved from the time of the stroke to the current day, and the changes in her and Jim's lives, roles and relationship, began to become apparent. However, as a result of the audit process, during which the study supervisor read the transcript alongside the early analysis, it was felt that the labels I had ascribed did not capture this effectively, and also failed to convey sufficiently the emotion and energy of Saskia's story. To move the analysis forward and enable fuller exploration of the data, and with agreement of the study supervisor, I created a large document on which clusters of related content from the early analysis and further revisiting of the text were listed. Supporting evidence in the form of text summaries or verbatim quotes, and my initial analysis were also documented thereon, and page and turn numbers were included to enable continued reference to the full text for additional context. In essence, this document enabled the events and changes that Saskia had described to be tracked in a phased fashion, but allowed connections between the phases and other themes to be made and fully explored. It also enabled the evolving analyses to be tracked by me and the study supervisor: as early analytical thoughts were refined and newer ideas about the data emerged, revised interpretations and superordinate theme titles were added to the table in a different colour. The headings from this document are featured in Appendix 3E and an extract from the document is provided in Appendix 3F. The study supervisor reviewed the document and the analysis. He noted the thoroughness of the examination and cross-referencing of the data.

Moving the analysis forward

The document described above enabled Saskia's unfolding and complex account of her experience to be accessed in a manageable way. Repeated readings of the document and my comments and analyses, with continued referral to the transcript, allowed new connections and interpretations, and some order of the range of concepts that emerged from the data, to be made. At this stage, it was obvious that the overriding and most important 'theme' in the data was the different phases in Saskia's and Jim's life, within which the changes in herself and Jim as individuals and in their relationship were entrenched. These phases, which encapsulate the content featured in Appendix 3E, are shown in Table 3.1. Included with each phase title is a verbatim quote, which captures the essential nature of the phase.

Table 3.1 Phases of Saskia's experience

Phase 1	Life pre-stroke: <i>'such a brilliant life'</i>
Phase 2	Jim's stroke: <i>'I'll look after him... don't take him please God'</i>
Phase 3	Rescue mission and hope: <i>'life was very sweet'</i>
Phase 4	Endurance, loss and hopelessness: <i>'it's a drudge'</i>
Phase 5	Regeneration: <i>'I want so much more from life'</i>

The findings of the study are presented in the above phased sequence. Saskia did not tell her story in this sequence or explicitly suggest that such specific phases exist. It was as I untangled the web of her story that the phases emerged in my understanding as major points of reference for Saskia. Though they are explored individually in the findings, it is important to note that the phases were more fluid than distinct, and that themes explored under one phase are echoed in others. The process represented by the phases was therefore both sequential and organic. Phases one and two are straightforward and comprise Saskia's memory of her and Jim's pre-stroke life and her memory of the stroke, its effect and her response to it. These first two phases formed only a small part of Saskia's transcript and have minimal bearing on the body of my analysis and findings. However, though largely descriptive, they are crucial points of reference: much of what emerges subsequently has a relationship with these first phases. Phase three and particularly phase four - in which Saskia was living at the time of the interview - are central to my understanding of her experience. The key concepts therein are related to Saskia's self image as the heroic 'rescuer' in phase three, and as 'just a carer' in phase four, which she perceived as meaningless and aimless in comparison. Phase five exists as a vision of the brighter future that Saskia held as an antidote to her feelings of dissatisfaction with her present life in phase four. Like phases one and two, this phase has a smaller contribution to the bigger picture, but is an essential link to the struggle of phase four.

Writing up

Analysis continued during the write-up. The process of translating the phases and themes into a narrative account required attempting to capture the complexity and most essential elements of Saskia's story, while paring away those that appeared peripheral. Thus, as part of the audit process, the report of the findings was examined and approved by the study supervisor, along with the document of themes and interview transcript. His feedback was that the narrative was engaging, evidenced and compelling and

captured the essential elements of Saskia's account of her experience. The findings are now presented.

6.3 Findings

In this section the findings are presented in the five phases already introduced. Verbatim extracts⁷ are provided to exemplify and elucidate the account given and to allow judgement of interpretations.

6.3.1 Phase one - life pre-stroke: *such a brilliant life*

Saskia described Jim as a man who was 'quiet, very controlled, liked things to be right... very hard working, very loyal'. He was a worrier and not very confident, quite introverted, the sort who, 'if you were out at a dance or a wedding, he would like to sit and watch everyone else, he wouldn't get up and participate unless he was really forced, and then he would enjoy it'.

Saskia talked of Jim prior to his stroke as 'Jim the Man', referring to him at all times as a man rather than a person, for example 'he was the type of man...'. She described Jim as being 'of the old school, where the woman did things in the home' and he had stereotypically 'masculine', activity-based job, hobbies and household roles. He was a motor technician. Work was important to him as the family provider and his employers held him in high esteem. He worked hard and loved it, to the extent, Saskia suggested, that he 'never took time out to enjoy life', though in his spare time he restored old tractors and farm machinery, enjoyed clay pigeon shooting and 'loved reading tractor magazines'. In the home, Jim looked after the cars, gardens and decorating. He was 'perfectly fit and healthy... never been to the doctors in his life'.

The sort of person Saskia described herself as before Jim's stroke seems very different to Jim: 'confident, very understanding, patient and kind, a people person'. She loved her job at the local benefits agency 'dealing with people who came in with problems', which suited her nature as 'one of life's copers' and 'a problem solver'. Saskia liked certainty in her life and was 'always one to plan'. She 'had taken control of the finances' prior to Jim's stroke, and saw herself as 'very independent-natured', the type

who would never ask for help. She was full of joie de vivre, felt young and fit for her age and loved horse riding and swimming. Saskia was also the homemaker and had enjoyed looking after her sons (now adult) and husband.

Saskia talked wistfully and with great fondness of her and Jim's life together before his stroke. They had been married for almost 40 years, during which time, she said, they had been 'such a great partnership'. Although they had pastimes independent of each other, together they enjoyed walking in the countryside surrounding their home, playing with their grandson, and socialising:

We had such a brilliant life before... we'd have sort of six weddings to go to in the summer and you were planning the weddings and looking forward to it, and Jim as well, we used to love it

In their life before stroke, Jim and Saskia rarely argued and their relationship was harmonious. A factor in this appears to be the clarity of their roles within the relationship: Saskia was the 'leader' in terms of financial control and the day-to-day organisation of their lives.

6.3.2 Phase two - Jim's stroke: *I'll look after him... don't take him please God*

The events surrounding Jim's stroke, over three years before our interview, were vividly remembered and described by Saskia:

... Jim came home on the 25th of May '99, he sat at the table, ehm, I was cooking a meal and, I spoke to him and- sort of garbled language came out, and I turned round and I realised immediately he was having a stroke... his face had dropped and he was dribbling

Saskia summonsed the doctor and their two grown sons, by which time Jim had partially recovered: he had had a transient ischaemic attack (TIA). The family drove Jim to hospital where tests were begun. During this time Jim had three more TIAs, before eventually having a 'massive stroke', which Saskia and her sons witnessed. She prayed to God to save him and promised to protect him if he lived:

⁷ In the extracts, underscoring depicts stress on the word; ... indicates elision; text in [] is explanatory

I was praying 'oh don't- don't let anything happen to Jim, I'll look after him you know, he'll be fine I'll look after him don't-... don't take him please God'

At the time of Jim's TIAs and stroke there were no medical staff present as they were searching for a bed for Jim, and it was Saskia who took responsibility for keeping them informed of Jim's deterioration. This period can be seen as the beginning of her taking control of Jim's care and recovery, the start of her role as Jim's 'rescuer'.

Jim's stroke was severe and left him with multiple impairments (the extent and effects of which are discussed in future sections). Saskia said that 'if you've never had any experience of strokes, you don't know what to expect'. Her early response to Jim's stroke was therefore to minimise it, and to believe that he and their lives would quickly return to normal. If Saskia had known more about stroke than she states (which may be possible given that she had recognised Jim's stroke), her minimising response, illustrated below, could be interpreted as denial. It is more likely, however, that she was innocent of the severe and long-term effects of stroke:

Immediately when he first had the stroke, we just thought 'oh gosh, he's had a stroke, never mind, you know, a couple of weeks, back to normal, and he'll be back at work, and life will be just the same'. You know I had no concept of what a stroke entailed, at all

Saskia's certainty that Jim and their lives would recover quickly was challenged by Jim's doctor's (ultimately correct) prognosis for him and for the couple's life:

The day after [the stroke] they said to us 'ooh you know your life will change now, it's not finished but it will be different', ehm, and although I never told Jim, they said Jim will never work again never drive again, well this was appalling... The nurses didn't agree with [Jim's doctor], and they said 'we don't agree, you know there's always hope'

Eight days later, when seeking more knowledge of Jim's stroke from his consultant, Saskia was told the same thing, with devastating effect:

I was absolutely dumbstruck. Dumbstruck and I-, I couldn't even listen anymore. Ehm, and I left his office and, a couple of the nurses took, ((begins to cry)) me into another room, and eh, I was devastated really. And they said, they didn't agree with what he'd said, or how he'd said it... and of course with all the months that went on from then, it did prove him wrong because Jim was walking well. Ehm

Q: So was that your first realisation in a way of what it meant?

Yes!, yes, yep, yep. And then the more people I spoke to like experts, occupational therapists and physiotherapists: 'no no no, we don't agree with that at all', and I said 'oh, thank goodness for that, they've put my mind at rest, things are going to improve'. Ehm, but, yeah it was a-, a shock

Q: And so... how do you then move forward with that; what happened?

Well, all I said was, 'you are not, to mention anything you've said to me to Jim', to the consultant, ehm, 'I don't want him to hear any of this. It will be counter-productive to his eh, recovery' ... I think if he'd said that to Jim at that stage eight days later Jim would have died, just given up and died, whereas he had us all chivvying him up

The quotes above indicate the enormous impact upon Saskia and Jim of both the content and process of information-giving post-stroke. Jim's doctors' prognosis that life would change was correct, but so early post stroke Saskia appears to have had no choice but to ignore it. She needed to hear – and could only listen to - responses from professionals that fitted in with her hope and belief for Jim's recovery and a return to normality, a mission for which Saskia was already establishing herself as leader. She therefore identified with the hopeful, perhaps more sensitively relayed yet ultimately over-optimistic, views of the 'expert' therapists, and controlled the information that she and others gave to Jim. She did this in order to protect him and ensure he had maximum motivation to succeed. However, this action could also be interpreted as disempowering Jim by overriding his right to know about his condition and prognosis. This section illustrates how difficult it is for professionals to deliver advice in a way that is sensitive to the individual needs of both its recipient and the person who the information is about.

It suggests that they should attempt to understand individuals' current views and needs in order to pitch their information sensitively, and with content that can be listened to.

6.3.3 Phase three - rescue mission and hope: *Life was very sweet*

Jim was admitted to a stroke rehabilitation unit, where he remained for four months. He had severe aphasia, short-term memory problems, was paralysed on the right side, dependent for all his daily care, and needed a wheelchair to get around. According to Saskia, Jim's personality had undergone a 'catharsis'. Whereas before his stroke he was reserved and shy, after it he became extrovert and 'child-like'.

In hospital Jim received regular physiotherapy and sporadic SLT. Saskia felt his nursing care and therapy were inadequate. She took control of his recovery plan, again asserting her own judgements over those of professionals whose opinions did not fit in with her own hope, need or drive for Jim's improvement:

They [therapy sessions] were very short and of course there was nothing at weekends... the weekends were just a waste, so I opted to bring Jim home on the Saturday morning, and take him back the Saturday evening, and I repeated that on a Sunday. And the consultant said 'oh no it's not a good idea, you're not experienced, Jim has no balance, he can't stand', ehm, and I disagreed I'm afraid, politely. I said 'Jim is getting no stimulation in here', ehm, so that's what I did, I brought him home every weekend for the four months, and friends came, and I played the music he liked, read to him, ehm, and I did work extremely hard. I also spent every day at the hospital, I used to go in in the mornings early, get him bathed, ehm, and we played games, I made coloured shapes, taught him the colours again... we played snap... I spent a lot of time, just giving him encouragement... and trying to get his brain working

... I poured so much into him, but in the end it did take its toll on me as well. I was very tired... I just felt the more I'm there willing him on, the more I'm speaking to him, doing things with him, the better his recovery was going to be

Several observations can be made from these extracts, which are also evident throughout the transcript. Just days after Jim's stroke, Saskia became the primary agent

of Jim's recovery and motivation. She took on caring and therapeutic tasks, which she approached with urgency, stoicism and an unrelenting work ethic. She saw Jim's recovery as a job to be done and a problem to be solved. All of this was in keeping with her self-image as a doer, a copier and a problem solver. Saskia kept up their home routine as well as Jim's care and focussed her energies on stimulating Jim, creating and playing games for him, which she felt would help him. The language Saskia used in the above extracts (and throughout the transcript) implied that Jim's role in his recovery was that of a relatively passive recipient of Saskia's rescue mission. This is captured succinctly in Saskia's statement 'we were pumping all this knowledge into him'.

After moving home Jim received outpatient physiotherapy and SLT, plus private SLT that Saskia had organised, all of which she felt were helpful: 'he did get on extremely well... he was progressing'. Jim's improvement drove Saskia on and fuelled her energy. It enabled her to continue to deny the doctors' negative forecast for Jim's recovery and their life change. The following extract illustrates how Saskia continued to protect Jim, and herself, from any suggestion that he and their lives would not return to just as it had been prior to his stroke:

I didn't let anything change at all and I think that was desperately trying to cling onto life so when Jim came back here [home] everything would be just the same... it was just a stiff upper lip ['stiff upper lip' were words borrowed from interviewer's], get on with it... keep everything as normal as possible so that Jim wouldn't feel he was a burden, or that he wasn't going to get better, and that things were going to be just as they were

In this phase of hope and recovery, Saskia was sure that she wanted Jim to live and she believed that she could lead him back to the life they shared pre-stroke. She enjoyed her mission, to which Jim was responding positively, to the extent that she said that 'life was very sweet' for them. Caring for Jim's daily needs such as dressing, bathing and shaving him were not problematic for Saskia. She did not see it as changing her role from that of wife to carer or nurse, but as a short-term aspect of her role as Jim's rescuer: 'it just seemed perfectly natural for me to help him do this until he got well again'. In a sense, given the extent of Jim's impairments and his negative prognosis, this may have been a period of denial for Saskia. Denial may have been a necessary coping mechanism for her at this stage. But it may also have been unhelpful, because, as she

had been advised, life *was* going to change. Accepting this might have helped Saskia and Jim to plan for the future in realistic terms and set goals that were achievable, instead of those which set them both up for failure and disappointment. However, as with the previous phase, Saskia's stated innocence of the long-term effects of stroke and the fact that Jim showed signs of making a recovery make denial equivocal in this situation. Saskia's mention of her experience of a short counselling course six months after Jim's stroke (the first time she had addressed her own need for help) sheds some light on the issue. From the short quote below, it can be seen that the conversations with her counsellor are likely to have increased her understanding of her situation and contributed to her conceptual terms of reference. However, it is less clear how resolved her feelings were or how unequivocal her views were. For example, she referred to acceptance without ever defining its subject:

... it was the counsellor who said 'you haven't accepted it you're still angry' and I was, yeah... she was quite right, I hadn't accepted it, but it wasn't something I could do next week, go in and say 'well I've accepted it now let's move forward'

It is possible that Saskia's counsellor had introduced her to psychodynamic concepts that she was yet to fully deal with or resolve at the point of our interview. It is also possible that Saskia was so focused on her rescue of Jim that she couldn't possibly 'accept' anything but a return to normality for Jim and her at this stage. Unfortunately I did not follow this up further during the interview so cannot comment more fully.

The final notable observation from this phase relates to Saskia's perception of Jim and of their relationship. It can be seen above that Saskia said that she made every effort to 'keep everything as normal as possible'. Although Saskia became Jim's rescuer and led his recovery regime, and although Jim was the more passive in the process, this was essentially 'normal' and in keeping with their pre-stroke relationship style. However, there were also aspects of this phase which marked the embryonic stage of, and fed the evolution of, a shift in Saskia's perception and treatment of Jim. Her creation of games for Jim to play which were essentially childish in nature, and her protection of him from unpleasant information can be considered a move towards a more matriarchal attitude towards him. The evolution and effect of this shift will be explored in the following section.

6.3.4 Phase four – endurance, loss and hopelessness: *It's a drudge*

14 months after Jim's stroke, his health and progress suffered a setback:

When we were pumping all this knowledge into him... he did improve, but sadly after, a year, he suffered at home a massive epileptic seizure... and that put him back, a long long way. I- I think there was quite a considerable amount of brain damage done through that epileptic seizure... that was in the- July. In the November, he had another one, it was even worse than the first one, and when the paramedics got here he'd actually stopped breathing, so had to be resuscitated, and I think a lot of damage was done then, and he never, he has never gone back to all that progress he made before he had that first epileptic seizure

Jim's seizures heralded the beginning of the most difficult and long-lasting phase in Saskia and Jim's post-stroke lives; one of loss, hopelessness and endurance. Unlike the phases discussed so far, in which Saskia's reactions and behaviours seemed mostly focused and clear, in the endurance phase (current at the time of the interview) her experiences were characterised by elements of ambiguity, ambivalence, confusion and uncertainty. Saskia and Jim's complex journey through this phase is now explored.

If this had been me who'd had the stroke I'd be running by now... but Jim just doesn't seem to make any effort

Saskia described what she saw as the main long-term effect of Jim's impairments on his participation in life:

It's altered Jim's whole life. He isn't mobile, he can't articulate, he knows what he wants to say I'm sure, but he just can't remember what he wants to say... he can't understand what he's reading, so that little bit of enjoyment he got from the shooting magazine and the tractor magazine, that's been taken away, all he can do is look at the picture... I think of it all, that's been the most devastating to him

At first, we were working towards his complete recovery, so he was buoyant and he was happy... while we were working towards his recovery and getting back to

work and getting to driving, it was, life was very sweet, if you like. I think now he's realised he's not going back to work, it's had a devastating effect... he enjoyed working, he loved it, and now I think he feels sort of useless. You know, he's said a couple of times 'me wish me dead'... ehm because he can't do anything

According to Saskia, Jim's feelings about and reactions to his disabilities changed over time. During the period of hope for recovery of his normal life, Jim was upbeat and buoyant, and reacted positively to Saskia's rescue mission. When this goal became unreachable, however, he was devastated, to the extent that at times he had expressed a wish to die. Jim's epileptic seizures and resulting loss of progress appeared to knock Jim's self-image irreparably. Saskia suggested that he felt useless and had lost any confidence in himself, and abandoned hope for recovery and any efforts towards regaining lost ground. Eventually Jim had accepted his fate and had become content with doing 'very little'. The extracts below are from several illustrating this. The second also highlights the corrosive effect that Jim's antipathy and regression had on Saskia's own sense of hope, and illustrates the interdependence of their feelings and behaviours:

... day after day he's just content to get up, and go off to class, or sit and watch something on the television, and when his meals come along he's 'ooh lovely', that's all his days consist of

... where he was sort of striding forward at first... now he appears to have totally given up... he's gone back, he's worse now than when he left hospital... no headway at all. It's very wearing, while you can see progress, even if it's slight or small, ehm, you've got hope, but now I feel I have none

The language Saskia used when discussing Jim's early progress almost without exception implied that she and her rescue mission were behind it. However, when progress ceased, she did not blame it on herself for a failed rescue. She acknowledged that the brain damage that Jim acquired during his stroke and seizures had created fundamental changes in Jim's personality and physical and mental ability, but she could not fully blame those changes for Jim's regression either. Instead, she believed that

Jim's weak character was to blame. She implied that if he had had her strengths he would have made a greater recovery:

Jim always lacked confidence and I think he still does, in fact worse, cause I said to him 'for goodness sake if this had been me who'd had the stroke I'd be running by now, which is probably an awful thing to say but you just can't help it when you're frustrated, but I honestly think I would be, but Jim just doesn't seem to make any effort...I feel like screaming

The total loss of that man

The above extract is important because it illustrates the evolution of the shift in Saskia's perception and treatment of Jim and in their relationship. During the rescue mission Saskia was patient and had become protective and matriarchal towards Jim. In this next phase, however, she remained matriarchal but became angry and frustrated with Jim's behaviour, which increasingly she saw and treated as 'child-like' or 'imbecile-like' (though see her response to the question in the fifth extract below). Concurrently, Saskia's enormous loss and longing for the pre-stroke Jim and their relationship - which was kept at bay while she was busy rescuing Jim and hopeful for his recovery - became palpable. With real pathos she described how the loss of 'Jim her man' and of his role as her husband was the greatest effect of his stroke for her.

... he's a different person... I think it's the brain damage, and he's almost reverted to being like a child. It's not Jim the man it's Jim the child... very sweet and ehm, sort of ehm, just quite sweet-natured and-, and, childlike... This man is sort of... not a man any more

I know he's here, heh, but I haven't got a husband. A husband you're a partnership... and we were, such a great partnership, but it's- we're not any more, it's all, one-sided... I've got 95% and he's got 5%

... it's a total change in my life because I haven't got a husband, ehm ((long silence and begins to cry))... I really want that man back ((crying)) you haven't got a husband, you've got a child, it's difficult to do things because this is a full-

grown man, ehm, and it's the responsibility of everything else... everything that a man normally does or you do together... it's the responsibility of everything

From his point of view I know, it [the main effect of the stroke] would be the reading and everything, but from my point of view, it's just the total loss of that man ((begins to cry))

Saskia felt the loss of balance in their partnership and that she now carried the burden of responsibility for their lives. She described a long list of her new responsibilities: for Jim's erstwhile roles in the home, for bringing in the money, for monitoring and protecting Jim's physical and mental well-being, and for ensuring she stayed healthy in order to be able to look after him. She also described loss of many other aspects of her and Jim's relationship. She missed conversation with Jim, no longer possible as 'he loses the plot along the way'. She missed the intimate side of their marriage, 'because sexually he has-that's finished', and longed to be needed as a wife/woman and 'not just as a carer'. She missed their erstwhile easy-going relationship, replaced with one featuring regular periods of antagonism and argument. The change in Saskia and Jim's relationship dynamic was evident within and through their communication. The extract below is one of several highlighting Saskia's frequent use of behaviour and language that a mother might use in dealing with a naughty child:

[Here Saskia is talking about trying to get Jim to do more around the house.]
I've spoken to him and he's agreed 'yes, yes I do that myself'... but within 24 hours it's totally forgotten... and then I'll get cross and say 'now come along'... and then he gets really angry... and swears, which of course before the stroke he would never do... Jim will shout and swear if you dare remonstrate with him... I think it's just sort of a naughty child's way of having a tantrum if you like, and 'if I do that perhaps she won't make me do it again'... sometimes I make a joke and say 'language Timothy⁸!'... it's just like a child

Q: Do you find yourself treating him like a child sometimes?

⁸ This is a phrase used frequently by a domineering mother to her adult son in a TV sitcom

Ehm, no, I will say to him 'stop acting like a two-year old, you're not two'... at other times I've said to him 'you're behaving as though you're an imbecile, stop doing it Jim, and he'll say 'I am, I will'; 'I will if I want to' is what he's saying

The above extract provides an example of Saskia's confusion about her relationship and interaction with Jim. She said she did not treat Jim like a child yet she showed by her language that she did. Jim's reactions also provide an important clue to the effect that Saskia's attitude and approach had on his behaviour and self-image. In the above, his responses to Saskia appear child-like. His shouting, swearing (which he knew upset Saskia), and his comment 'I am... I will if I want to' to Saskia's demand to stop behaving like an imbecile appear to be Jim's attempts at exerting his rights and regaining some power. He may also be saying: 'you treat me like an imbecile, I feel like an imbecile, so I am an imbecile'.

I need to be needed, but not just as a carer

There was a marked difference in Saskia's description of and attitude towards caring for Jim's daily needs during the rescue mission and in the endurance phase. At first, she took pride in bathing, shaving and dressing him; her descriptions of doing this in hospital evoked a sense of an honourable crusade. But her enjoyment of looking after Jim evaporated along with the hope for his return to normality and the chronicity of his disabilities. In the endurance phase, Saskia saw her role as having shifted from that of rescuer to carer. The following extracts illustrates the rescue/care dichotomy, her reluctance to carry on as carer, and the corrosive effect that the caring role in the long term had on Saskia.

It seemed just perfectly natural for me to help him do this [bathing, shaving etc] until he got well again; that's the difference - now he's never got well again and I'm still doing it, and it's a drudge

Prior to Jim's stroke, Saskia led an active and fulfilling life. This continued, albeit in a different manner, during the rescue mission when 'life was very sweet' and she was busy with Jim's therapeutic activities. But in the longer term, Saskia felt she had lost her life. She stated:

We had such a brilliant life before... but now, nothing- we don't seem to have much in the way of this day-to-day existence

Saskia lost and missed freedom and spontaneity ('our life is such a pattern'), and yet was also upset that she could no longer fulfil her need to plan for future activity because of Jim's disabilities. Her life was now 'so different... sort of in limbo':

You want to be happy, and although people say, you know-, you're alive, so you can be happy, that's ridiculous if you've always been people that have done things, active people that have planned, and looked forward to things that you can't do any more... it isn't what you want, it isn't what you need. We- we need- we need to- you need to see somebody fit and well... I want to be able to go walking together again... I suppose it's the things we used to do, which we can't do...

Q: Mm, so you want your old life back

Yes I do, yes

It was not enough for Saskia just to be alive; happiness meant her life as it had been. However, feeling responsible for Jim and guilty if she left him alone too often, left her reluctant to do more than the part-time work and swimming and riding sessions which she allowed herself in order to 'get out of this disability mode and do something normal'.

Saskia had a strong self-image before Jim's stroke: she was a confident doer, copier and problem-solver, and she was active, fit and healthy. A marked change, which Saskia attributed directly to her role as carer, was to her health. She said: 'I could probably count the times on one hand I'd had off work in ten years, but the stress and strain of looking after Jim has caused my health to deteriorate'. Shingles, Bell's palsy and a hernia (from lifting) were on Saskia's list of recent illnesses. But perhaps the most devastating consequence for Saskia of the shift from the rescue mission to the endurance phase was the transformation of her perception of herself as a vibrant, confident, kind woman to 'just a carer', 'a drudge', 'a changed person', who had lost

her capacity and energy for empathy. In short, Saskia felt that in becoming a carer she had lost herself:

I know I'm sort of 58, but... I need to be needed, but not just as a carer... I do enjoy my home and the garden... but sometimes I feel a drudge ((tuts, begins to cry))... you just feel- ((sighs)) I think, I have this basic need like a lot of women do, you need to be needed, for yourself, as a woman... you want to feel cherished and treasured as I was before... but you're not any more. You're just, a carer, you're humping wheelchairs... you're getting the bath hoist in and out of the bath... and then your husband's in bed at 7 o'clock, and you sit here in this lovely place and you feel empty. That's how I feel, empty

Before [Jim's stroke I was] confident ehm, very understanding... a people person, ehm, what happens now is, I suppose because I'm tired, I haven't got this really satisfying life any more, because of the drudgery of caring for Jim, and I'm impatient with them, the people at work, I'm not the same person at all, ehm, and I was always so full of life and I'm tired now, heh, ehm, so, yes I'm changed as a person, because, because I feel empty, because I-, because I would like my life back as it was

The extracts above contribute to the sense of endurance that pervaded this phase, and illustrate Saskia's resistance to and reticence at her role as carer and her longing for her pre-stroke life. The romance in the words she used to describe how she felt before (cherished, treasured) is in contrast to the stark labels with which she described herself as a carer (drudge, empty). Ultimately, she blamed Jim's behaviour and needs for the loss of her life and herself. But she was also disappointed that she had 'failed' to cope with or solve Jim's problems as she would have done others. However, as the following extract illustrates, Saskia recognised that Jim's difficulties could not be overcome using her erstwhile successful problem-solving formula because his stroke - ie its long-term and unretractable effects - could not actually be 'mended' no matter how hard she tried:

I feel a failure... and guilty because I'm not able to cope, where I always one of life's copers. Everybody came to me with their problems, and I'm a problem

solver. You go back to the root cause and you, you know, fix it and hey presto, it's mended... but of course this [stroke], is not like that

Saskia liked certainty in her life and planning for the future. These aspects of her character were undermined not only by the effect of Jim's impairments, but also by the uncertainty over Jim's future. Saskia found this so difficult to live with: would he die, and when?

I think the worst thing for me is not knowing what the future holds. I mean they told me that Jim won't live to be an old man ehm, if we got past the first six months, you know he stands a chance of, sort of-, a few years, but he wouldn't live a long time. And I think that's been difficult because I sort of-, ehm, ((begins to cry)) sort of every day it's you know ooh we've got another day now... you wake up in the morning and think, ((in a whisper)) 'oh, yes, he's alive ((sigh))', which has been hard

The extracts above again suggest that it was a complex combination of and relationship between the impact of Jim's needs and behaviours upon Saskia's lifestyle, Jim's impairments' resistance to Saskia's problem-solving strategies, and the uncertainty over Jim's future, that were so pernicious to Saskia's self-image. In summary, Saskia's previously positive self-image and self-esteem were gradually eroded by the caring role which, once hope of recovery receded, she perceived as drudgery. She had a sense of failure in her rescue mission and resented the way the drudgery impinged upon her vision and achievement of a more meaningful life. On top of all this, she felt a loss of control over the future, particularly in relation to Jim's quality and length of life.

I can't be bothered any more

Saskia became so disappointed and despondent with Jim and his lack of progress that she abandoned her rescue mission. She implied that Jim, in giving up himself, was responsible for her doing so. Whereas in the rescue phase Saskia was able to ignore her tiredness, at this stage it finally overcame her and became a catalyst for giving up on Jim:

... for two and a half years I just put everything in, and then I was just so tired I thought one day, I can't do it today... so I left it, and then it was easy to leave it the next day

I've almost stopped [pushing Jim] now... I feel so disappointed with him, and angry, because he's not trying, and I feel disappointed for myself because I wanted us to be doing things, not just languishing until the day Jim dies, ehm, so I'm disappointed in him and for myself... and because I'm tired now from all this work I've put into him, I just feel like saying 'well I can't be bothered any more', which is awful really, but I really don't feel I can put much more into it you know it's got to come from Jim and I can't see him doing any more... I should say if he's quite content just to do what he does, which is very little, then leave it, but I want so much more out of life

The second extract above, and the three following, illustrates the desperation and confusion of Saskia's feelings and views in the endurance phase. She felt anger and disappointment at Jim's inabilities and did not want to be a martyr to his hopeless cause. She resented his lack of motivation when she had worked so hard, so began to defer responsibility for recovery to him, in effect setting him up to fail. However, challenge and intolerance now replaced her patience and encouragement of the rescue phase:

I've accepted that Jim has had the stroke and that he won't work again and he won't drive again... but I still want Jim to try and be a little bit more mobile, I want Jim to go forward, I don't want him to stick here doing nothing, so although I've accepted it... I still want him to keep trying but you see he says 'I am'... but it isn't my best... if that's your best do better

He's quick to tell me as often as possible, 'I don't want to go back to that man [physiotherapist], I don't like that man... I don't want to go', I say 'you are going, because these people are helping you'. But he totally balks at being pushed, and that is what's now made me very cross

[talking about doing jobs around the house]... *I've tried, ehm cajoling... being nice about it... and he always agrees 'yes I will do that ...', but then just doesn't do it, and now I'm getting cross... because I want him to make the effort, to do it himself, because... the more I do for him the more I can see he's not doing, and isn't going to improve and I don't want that... I don't feel like being patient and kind sometimes, I feel like giving him a good kick up the bottom... I've pampered you enough! You get on with it!*

It can be seen above that alongside Saskia's change in attitude to Jim, she retained power and control in their relationship. Driven by her continued longing for more from their life, she could not allow Jim to admit complete defeat. She did not recognise Jim's right to choose: he was not allowed to reject physiotherapy or, for example to use a wheelchair indoors, because these implied cessation of progress and a bleak future. Finally, the above extracts also provide evidence of the widening division between Saskia and Jim's wishes and needs and in their communication during this phase, and hint at the suffering Jim experienced.

Able to move forward

It can be recalled that Saskia had been made aware of her non-acceptance during the rescue phase, but that she had not defined or explored it more fully then. Saskia felt that she had reached acceptance during the endurance phase, but it was evident from her talk that this was equivocal, that the concept remained undefined and uncertain, and the process of acceptance unclear. For example, she said that as time had gone on she had got 'more and more used to it and accepted things as they are', had 'got rid of the anger' and therefore had been 'able to move forward'. She said she was unsure of how she had reached this state: 'I can't tell you what caused it... I thought... I have accepted it, and this is how life's going to be, we must just enjoy each day'. There is much evidence in the data quoted so far to suggest that Saskia retained anger and a longing for life to change, and was not enjoying each day. It is possible, then, that Saskia's talk of acceptance was rhetoric, or perhaps she had indeed reached a *degree* of acceptance, ie had assimilated aspects of Jim's disability into her life, such as him not working again, but not others.

Until the endurance phase, Saskia's independent nature had largely stopped her from asking for or accepting help (though she had sought counselling early on). However,

two years after Jim's stroke she accepted an offer of respite care for Jim, to which he went reluctantly three times a year. She knew he hated going but recognised the need for herself to have a break from caring, 'because if he's not going to improve, all I can concentrate on now is keeping myself fit and buoyant, because if I go down, go under, then we're not gonna get anywhere'. This is another sign of Saskia's 'moving forward' and 'letting go' of Jim. While Jim was in respite-care, Saskia took holidays with a friend:

... we've been to Tenerife we've been to Spain... I come back so refreshed and I can't wait to go up to bring Jim home, and I'm buoyant and happy, and he's trying because he's missed me, ehm, but then it gradually gets, you know, harder and harder

This extract suggests that Jim may have experienced these respite periods as punishment (ie trying harder upon Saskia's return), but that they regenerated Saskia. Though they boosted her ability to cope with looking after Jim, at least in the short-term, they also gave her a taste of the 'good life' she was longing to return to, and proved to her that she could enjoy that life without Jim. This is explored further in the next section.

6.3.5 Phase five - regeneration: *I want so much more from life*

Although at the time of the interview Saskia was enduring her life as a carer, she had a vision for a future that did not include Jim. This was a future that was bright and constructive and would restore her degraded self-image and lifestyle.

At the time of Jim's stroke Saskia prayed to God to save him. During her rescue mission she was certain that she wanted to and could save Jim herself. During the endurance phase, however, when Saskia came to believe that Jim's life (greatly impaired and unsavable) and her role as carer (as opposed to rescuer) were both meaningless, her feelings about Jim's future changed: she sometimes wished he would die. The following extracts provide very honest and telling evidence of Saskia's death wish for Jim and of her belief that his death would enable her to regain a sense of certainty and positiveness that were inherent in her character and life before Jim's stroke and to which she needed and longed to return:

I've thought several times since Jim's had the stroke, 'I wish he had died that night' ... Now, after all that's happened... I do wish Jim had just, had that stroke and died, because... we've had such a good life together, and I've had all those memories to draw on, whereas now, I'm going to feel guilty, because I didn't cope, ehm, ((begins to cry)) and guilty because I- thought, I wish he had died, ehm, ((sounding stoical)) but I shall try not to

I can't go further forward than today really. I mean, ehm, the farthest forward I go is booking the car in for a service or booking a hair-cutting appointment. I can't think any further forward than this really because I just don't know what the future's gonna hold. And I think that's very difficult when you've always been one to plan... I just feel I'm in limbo, I can't- cause I don't know whether Jim's going to be here much longer, I don't know whether I'm going to be on my own, ehm, I think, if I'm absolutely truthful, it feels awful to say it, but when Jim does die it will be a relief, in a way. Ehm, a relief and a release

Saskia felt guilt in acknowledging the relief she would feel when Jim died but, as can be seen below, she dealt with her conflicting feelings of guilt and hope for the future by drawing on rational analysis and the support of her sons and friends. And of course Jim himself had expressed a wish to die. Saskia had prepared herself for Jim's inevitable death, which she had been expecting since the early days post-stroke. She also knew that she could enjoy life without Jim:

... [my sons] have both said... they didn't mean it nastily but ehm, Jacob said 'I hope Dad doesn't live for years and years and years like this Mum... I couldn't bear to see him get worse and get bed ridden', and Mark has said exactly the same, but for my sake... he said 'I want to see you have a life again Mum... you were always so full of life and now you're looking so tired... [he] said 'I want to see you, being able to enjoy life' and I said 'well, do you think I would be able to enjoy life if Dad died?' you know? ehm, he said 'yes you would Mum you'd pick up very quickly'

Q: Do you think you would or-?

From when we're on holiday [while Jim is away for respite care], ehm, Rosie and I, we do have such good fun, and I come back so full of, joie de vivre if you like I- I feel so rested, but then I know I'm going to pick Jim up you see and I'm eagerly driving up there to pick him up and get him back... ehm, but then as the weeks go on you get tired again, so I don't know-, I think-, because I've expected it for so long, I would wake up and think 'oh gosh!, oh yes he's breathing today. Good. Okay we're alright', I think because I've expected it so long, I don't think it's going to be such a shock when it happens... I think I will, pick myself up very quickly, once the awful trauma is over... and that-, I don't mean to sound heartless saying that, I've just sort of tried to nurture strength of spirit if you like because I know the inevitable's going to happen... but I hope I'll get over it, quite quickly, and be able to sort of, you know, get on with life

Though Saskia feared Jim's death in one sense, she was able to justify and rationalise Jim's death on several dimensions, including vindication by her sons. She dealt with her sense of failure (in rescuing Jim) in a similar way:

... I felt a failure because I haven't coped, but really I know I have done my best, and both our sons say, 'you couldn't have done more', and I have to tell myself, 'that's right, I really could not have done more', and even though I've been impatient sometimes and eh, perhaps been, you know crabby with him and eh, you know, I have done my best... What would I have done different? Nothing you see I can't think of anything... so, realistically looking at it that way, I should feel that I've done the best I could, the best job I could and not to feel guilty... but human nature's a funny thing

In dealing with her guilt both in relation to believing that life would be better if Jim was dead and to her sense of failure, Saskia's arguments were characterised by elements of ambivalence and ambiguity, so no matter how strong her rationalisation, she was left with feelings of residual guilt. The final extract above shows Saskia's insistence that she had done her best for Jim and could have done no more: it shows that intellectually she knew she was not a failure, though emotionally she felt one. She did not pin down what failure was, so several interpretations could be made from her words here. For example, they could imply that the failure was not hers, but Jim's, or that in 'doing her best' she had not failed. Saskia's choice of words 'my best' and 'the best job' to describe her care

of Jim could tell us that what she had done was the best *she* could do. However, her co-occurring sense that ‘human nature is a funny thing’, in preventing her from feeling guilt-free, could be interpreted as Saskia’s intuitive sense that her best job was not actually the best for Jim.

The above findings are summarised and discussed below, with reference to existing literature.

6.4 Discussion

The aim of this study was to understand Saskia’s experience as a partner of a PWA. It can be seen from the findings that Saskia painted rich and vivid pictures illustrating complex issues and profound effects resulting from Jim’s stroke, for which his aphasia was only partly implicated. Saskia described so many facets of her experience so eloquently, that discussing each of them individually and in depth could be justified. However, it seems more appropriate to focus primarily on the concepts that appeared pivotal to her experience and which are the essential themes that relate to the process of change over time. These include shifts in Saskia’s perception of herself from ‘dynamic rescuer’ to ‘burdened carer’, of her and Jim’s roles and relationship from those of husband and wife to something ill-defined but akin to mother and child, and Saskia’s mechanisms of coping through the change process. These are now discussed, with reference to existing theoretical literature. The discussion concludes with a critique of the study and consideration of the implications of the study for clinical practice and future research.

6.4.1 Life pre-stroke: Saskia and Jim the partners

Saskia’s account of her experience has been presented in a way that captures the complex process of psychosocial change that she and Jim experienced from the time of his stroke to the present day. The point of reference, from which subsequent changes emerged and were compared, was Saskia’s perception of her and Jim’s life pre-stroke. She painted a picture of an idyllic time of certainty, when Jim’s and her husband-wife roles were as solid as rock and their tasks and responsibilities were clearly defined in an unwritten contract of their functional partnership. Jim was a man who undertook traditional male tasks and deferred most substantial responsibilities to a highly

competent woman. Clear roles and a positive self-image were essential to Saskia's happiness.

6.4.2 Jim's stroke and rescue: Saskia the rescuer, Jim the victim

At the time of Jim's stroke, Saskia felt uninformed about and unprepared for dealing with the aftermath of it, a perception mirrored in Anderson's (1992) study. However, from the beginning and in the days and months that followed the stroke, Saskia's competence was strikingly evident as she tackled Jim's hospitalisation and organising his rehabilitation. Saskia became Jim's 'rescuer', and Jim the 'victim' to be saved. The concepts of 'rescuer' and 'victim' here are adapted from Karpman's (1968) transactional analysis model of 'drama triangles', which has been applied to thinking about situations of heightened emotions and disturbance (Hughes and Pengelly, 1998). In summarising Karpman's definitions, Hughes and Pengelly (1998) state that:

'a person in the rescuer position can bear neither vulnerability nor hostility in her/himself. A 'persecutor' is therefore sought who can be blamed for all hostility. Meanwhile the 'rescuer' projects all vulnerability into a 'victim', who the 'rescuer' omnipotently sets out to save with panaceas that will remove both hostility and vulnerability from the scene – a project doomed to fail, leaving the 'rescuer' seeing most authorities as oppositional and persecutory' (p101).

Saskia's rescue behaviours were totally in keeping with her self-image as a copier and a problem solver and with her pre-stroke roles. To rescue Jim she would mobilise all the qualities that made her an effective and powerful wife and would overcome all barriers that the world put before her. Through this, Saskia maintained a positive self image and, in her eyes at least, their relationship remained sound. This romantic description is not provided to detract from Saskia's honourable commitment to Jim, but to illustrate two points that are crucial to understanding the problems evident in the subsequent phase. First, this picture was all about Saskia and her crusade: Jim was portrayed as the object of her mission (ie the victim). From Saskia's descriptions, there was no sense of Jim's participation or engagement in planning or driving the mission forward. Indeed, it could be said that Saskia showed signs of over-protection at this stage, a commonly-reported feature of post-stroke relationships noted in Chapter 2.4.3 (Christensen and Anderson, 1989; Habgood and Hesketh, 1996). Second, by its nature, a rescue mission is only successful if the victim is saved. Saskia defined 'saved' as getting back to their old,

idyllic, life, contrary to the hospital consultant who, soon after Jim's stroke, told her this was not possible. Saskia's reaction to him suggested she saw this harbinger of doom as fitting the drama triangle's status of 'persecutor'. She was determined to prove him wrong. Some previous research has suggested that information given by hospital staff to relatives tends to be vague because of the unpredictable nature of recovery or is focused predominantly on the short-term and related to discharge (Pound and Ebrahim, 1997). This did not appear to be so in Saskia's case: she perceived that the doctors she spoke to were brutally honest and specific in their bleak prognosis for Jim's future. Though not probed during the interview, it is possible that the content and delivery of their information may have fuelled or even spawned Saskia's mission. However, Saskia's account suggests that further research into the effects of information-giving on partners' reactions and coping behaviours may be useful.

Saskia's coping during Jim's stroke and rescue mission phase

To some extent the rescue phase was a 'honeymoon' period, in which Saskia's romantic vision and strong motivation created transitional roles and images that swept her and Jim along towards an imagined return to pre-stroke certainties. Looking at that time from within models of coping introduced in Chapter 2.4.8, it could be suggested that Saskia's actions and reactions in the rescue phase implied she was in a period of 'denial', as defined in Tanner and Gerstenberger's (1988) model of loss and grief. For example, Saskia believed that Jim's problems would be completely overcome, and she could not accept information to the contrary. However, there was no more evidence than that to confirm the existence of denial: Jim did show signs of recovery in those early days. It is also possible to see Saskia's actions as examples of 'problem-focused' or 'active' coping strategies, described in the literature review as being used in situations that are amenable to change (Folkman and Lazarus, 1991) and as 'adaptive' (Elias et al, 1987, Barusch, 1988; Kendler et al, 1991). Such strategies have been found to be used most by men and those with higher income and education (Pearlin and Schooler, 1978); to a degree then, they can be considered to fit with Saskia's self image as a competent problem-solver and with her overall status.

6.4.3 Endurance, loss and hopelessness: Saskia the carer, Jim the cared-for

In the next phase of endurance and, ultimately, hopelessness, a new picture emerged as it became apparent to Saskia that Jim was not going to be saved or make the kind of

recovery that she had envisaged. This was the point at which Saskia had to face the cold reality of the emerging questions: 'who and what is he?', 'what does that make us?', and 'who and what does that make me'? These questions were not asked explicitly by Saskia but they capture the dilemma at the heart of her experience; that related to changes in her and Jim's respective roles, their relationship and in Saskia's self image during this, the longest and most profound of all the phases. Despite struggling with these concepts constantly she was never able to adequately answer the questions they posed. By definition, Saskia could no longer be the rescuer. Consequently, as her frustration and resistance to her own self image as a 'failure' (in the rescue) grew, she began to attribute characteristics and roles to Jim that would enable failure to be more easily deferred to him and his weaknesses. She spoke of his lack of motivation and abilities, and referred to him as an imbecile and child-like and suggested he was over-emotional, angry, resistant to the remedial strategies with which she persisted. Saskia's hostility to and criticism of Jim indicate her negative attitude to him in this phase. Negative attitudes have been recognised in previous literature (eg Zraick and Boone, 1991; Le Dorze and Brassard, 1995) (see Chapter 2.4.3) as contributing to the severity of stroke survivors' depression (Weddel, 1987) and decrease in their self-esteem (Gainotti, 1997).

Saskia used many of Jim's behaviours to support her redefinition of their relationship and roles and to abandon the notion of them as husband and wife. She now perceived herself as the (reluctant) 'carer' and Jim as the (undeserving) 'cared for'. Though in some ways Saskia's terminology in describing this shift captured elements of the relationship between a carer and another adult who is physically dependent after stroke, the closest Saskia came to adopting role terminology was to that of a mother-child relationship. None of the literature reviewed in this thesis so far has suggested this shift in perception so explicitly or dramatically. This may be a result of previous studies using methods which did not tap into individual perspectives' or language: the closest references to stroke survivors or PWA becoming 'children' was Zraick and Boone's (1991) mention of 'immature' as a characteristic attributed by spouses. However, in a more recent life-narrative study of the experiences of ten spouses of stroke survivors, interviewed in the acute stage, at six months and one year following their partners' stroke, Ellis-Hill (2001, p50) suggested that 'wives often spoke in terms of returning to a parent-child relationship'. Even that qualitative study, however, did not highlight such change for individuals or the language used as articulately as Saskia does herein. The

single case and analytical methodology of this study has enabled the quality of Saskia's contributions to be heard (Smith, 2004).

Saskia's references to mother-child can be seen as a sign of her ongoing confusion and desperation, and a search for language that would express Jim's new persona and their new relationship. She may have clung to this concept because it is familiar and no adequate terminology exists, certainly within a coherent social discourse, to capture her and Jim's state. Ultimately though, the prescribed mother-child roles and discourse could only fail Saskia and enhance her frustration, because Jim is not Saskia's child and Saskia is not Jim's mother: their related terms belong in an entirely different setting. In addition, Jim may have done some things that were child-like, but a child with Jim's specific intellectual, speech and language, and physical characteristics is unlikely to exist. Similarly, Saskia may have carried out tasks that were mother-like, but her attitude towards Jim was not maternal in the nurturing sense; she knew that his development did not progress like a child's. Perhaps a particular tragedy of this phase and the role problems described is the lack of an adequate terminology and discourse that would provide the appropriate words to describe the relationship that Saskia and Jim found themselves in.

In the endurance phase Saskia spoke resonantly of the 'unremitting burden' of her caring and household responsibilities, to which much previous literature has referred (Twigg et al, 1990). Some recent literature has suggested that carers will describe rewards of caring if the research method allows for a broader focus than that of burden (Nolan, 2001). Despite the interview being 'open' enough to offer Saskia the opportunity to report positive aspects of her experience, there was no evidence of this in her account. It was plain that she saw the long-term carer role as uni-directional, meaningless and aimless. And while her fundamental image of herself as dynamic and pragmatic fitted with her rescuer phase, it was incompatible with that as carer. She was determined to resist both the role and the 'drudge' it had forced her to become.

Some studies featured in the literature review suggested that partners' general attitude to caring is influenced by social, cultural and familial assumptions (Anderson, 1992; Twigg and Atkin, 1994), for example caring may be provided out of love, obligation, guilt or a lack of alternative. Saskia did not describe her role within those concepts, but

a discussion about them may have provided further rich material about the extent to which these may have influenced her experience.

Loss

It was in the endurance phase that Saskia's profound sense of loss emerged. She felt loss for so many things. She felt loss of conversation with Jim, commonly reported in previous literature (eg Le Dorze and Brassard, 1995), and to be expected given the extent of Jim's aphasia. However, there was no sense that it was their communication difficulties that most affected the quality of Saskia and Jim's relationship, a finding also noted by Anderson (1992). Nor did it appear to be the major contributor to role changes, Saskia's psychosocial distress, or sense of loss, which has been suggested by some previous research reviewed in Chapter 2.4 (Artes and Hoops, 1976; Christensen and Anderson, 1989; Johannsen-Horbach et al, 1993). Saskia felt loss for the lifestyle and social activities she had enjoyed both as a couple and independently, another commonly reported outcome of becoming a carer (Malone, 1969; Malone et al, 1970; Artes and Hoops, 1976; Holbrook, 1982; Anderson, 1992; Le Dorze and Brassard, 1995). She felt loss of intimacy and partnership (also noted by Kinsella and Duffy, 1978, 1979; Williams and Freer, 1986; Sparkes, 1993) and of course for their relationship. Some research has suggested that a problematic pre-stroke relationship may exacerbate post-stroke dissatisfaction with life (Anderson, 1992) but that a positive premorbid relationship may ameliorate distress (Hart, 1994). This latter suggestion does not appear to fit Saskia's case. Saskia described her and Jim's premorbid relationship as happy and solid, but rather than buffering her distress, that relationship was always held up in the background as an ideal to which she could not return, and against which all other states were seen as negative.

Saskia felt loss for Jim 'the man', but perhaps most profoundly she felt loss for herself. Where prior to the stroke she was strong and active, her role as carer had caused her to become fatigued and prone to illness: another well-reported concomitant of caring (Whitehall-Smith, 1977; Brocklehurst et al, 1981; Hart, 1994; Steptoe, 1997). She spoke of the insidious creeping of fatigue, adding weight to the argument that carers become exhausted with the 'wear and tear' of care-giving, as opposed to adapting to it and becoming less distressed over time (Holbrook, 1982; Wade et al, 1986; Carnworth and Johnson, 1987; Schulz et al, 1988; Townsend et al, 1989; Hart, 1994; Smith and Schwirian, 1998). She eloquently described the painful recognition that providing long-

term care for Jim had transformed her from a vibrant, empathetic woman into an empty drudge, 'just a carer'. None of the research referring to carers of stroke survivors featured in the literature review described the effects of the caring role on their self-image. However, changes to the self-image of PWA were discussed in Chapter 2.3.2. In this, it was noted that identity (which is linked to, among other attributes, social roles and membership of groups (Baumeister, 1995)) is based on feelings of personal sameness and that we become 'depersonalised' when events or circumstances threaten that (Rosenberg, 1987). Saskia could be seen to have become 'depersonalised' as a result of becoming a carer. This finding is mirrored in Ellis-Hill's recent (2001) qualitative study. She noted 'fundamental identity change' for partners in the longer term (p48). Despite this, it can be seen that Saskia attempted to retain her positive self-image (Markus and Nurius, 1987) by attributing the failed rescue mission to Jim's characteristics rather than hers.

Coping during the endurance phase

Returning to the theoretical coping literature reviewed in Chapter 2.4.8, Saskia's behaviours and actions of the endurance phase can be seen to have changed from those she exhibited during her rescue mission. On Tanner and Gerstenberger's loss and grief model, Saskia's account suggested she had moved from any denial of the early days and months post-stroke, into and through the stages of frustration and depression. Saskia did say she had also reached a point of acceptance at this stage, but there was evidence in her talk about the present and future to suggest any acceptance was, at most, only partial. Because these concepts were not probed in depth further during the interview, it is not possible to draw firm conclusions about her behaviours within the loss and grief model, though this may be a useful avenue for future research.

Whereas in the rescue phase Saskia used problem-focused coping strategies, there were signs that in the endurance phase she used more emotion-focused strategies, such as disengagement (Pruchno and Resch, 1989). The most obvious example of this was her withdrawal of effort into Jim's rehabilitation. Avoidance strategies such as this have been considered maladaptive (Elias et al, 1987; Barusch, 1988; Kendler et al, 1991) and associated with perceived burden and duration of care-giving (Killeen, 1990). Saskia's use of them may therefore be an indication of her difficulties adapting to her new role and of her perception of burden.

6.4.4 Regeneration: regaining control

Saskia could not deal with the muddle of her present situation. Jim's stroke and later seizures meant that she was living with the possibility of his death as part of her daily life. Ellis-Hill (2001) noted such a finding in her work about carers of people with chronic and terminal illness. Saskia found the uncertainty of when Jim's death would occur hard to bear. This uncertainty prevented her from fulfilling her need to plan ahead, as befitted her nature. Ellis-Hill (2001) noted research suggesting that not being able to plan or move towards personal goals can lead to psychological distress.

In order to circumnavigate her uncertainty and the role, relationship and identity problems in which Saskia appeared to be stuck during the caring and endurance phase, she created a vision of a future in which her role and self-image became that of a 'survivor' of Jim's 'hopeless case'. In this phase of 'regeneration' Saskia projected to a future in which Jim was dead and she survived to regain a positive image of herself, compatible with the women that existed before the stroke. However, she did this at some cost, because this image meant abandoning Jim to his inadequacies and his and her own death wish for him, and managing her discomfort and guilt about this.

Paradoxically, this enabled Saskia to regain a sense of control and certainty about the future that she could not achieve, and felt such loss for, in the present. This may have been the result of her strategy of using wishful-escapism focused coping or fantasy, which some research has suggested are used when situations are perceived as uncontrollable (Blanchard-Fields and Irion, 1988; Lutzky and Knight, 1994). However, it may also be because she already had 'evidence' (from her son's comments and her holidays with a friend) that she could survive, nay thrive, without Jim. It may be reasonable to assume that this positive vision of the future is crucial to the mental health of people who have personalities like Saskia's and who are in the same phase of 'care and endurance'.

Summary

To summarise, this discussion has focused on Saskia's shifting experience of psychosocial change resulting from her husband's stroke. A central aspect of that experience was its phased nature. Saskia began her post-stroke 'career' as Jim's partner and wife. She became his rescuer, a role that appeared to emerge from her own self-image and personality. Though part of that role included providing care for Jim, she saw that as a short-term duty that would only last until Jim got better. However, Jim did not

get better, and the chronic, intractable nature of Jim's stroke illness and related disabilities cast Saskia into the long-term role of 'carer'. It was this role which appeared to have such a destructive effect on Saskia's self-image, and, it would be reasonable to assume, on Jim. However, Saskia foresaw a brighter future, once Jim was dead, in which her pre-stroke self would be restored.

The findings and discussion documented the process of change in several inter-related facets of Saskia's psychosocial experience. They illustrated Saskia's evolution from partner/wife to burdened mother/carers, Jim's evolution from man/husband to 'child'/'cared-for' and the resulting changes in their relationship dynamic. They suggested ways that Saskia coped with those experiences and resultant losses by reference to theories of loss and grief, and coping. The conclusions and clinical implications of the study and directions for future research are provided after the critique of the study that now follows.

6.5 Critique of the study

6.5.1 The sample

It is recognised that the sample in this study comprised only one participant, Saskia, and that the findings are therefore unique to her. The sampling was 'purposive', that is based on 'the researcher's judgement as to typicality or interest ... to satisfy ... specific needs in a project' (Robson, 1993, p141). Obviously the study does not address the experiences or needs of other wives who may be living with and caring for a PWA, or those of male spouses or other relatives, whose needs and experiences are likely to be different from Saskia's (Horowitz, 1985; Zarit et al, 1986; Christensen and Anderson, 1989; Hart, 1994). However, the benefits of studying this single case and using the IPA method, was the breadth and depth of the issues it was able to reveal and explore, and thus the exposure of an immensely full and rich picture of complexity. Such richness was not achievable, for example, in Study Two, or in any previous studies reviewed, which featured larger numbers and greater distillation of data and/or methods less suited to uncovering personal experience in such depth and quality.

This study aimed to develop an understanding of what was important about the case rather than to produce generalisable results. However, it has been recognised that case study can be seen as ‘a small step toward grand generalisation’ if the case is presented in sufficient detail so that the reader can make good comparisons and draw their own conclusions about the findings’ generalisability to other cases (Stake, 1998; Smith, 2004). It is hoped that the provision of a detailed account of Saskia’s experience, backed up with verbatim quotes, and discussed with reference to the literature, has enabled such conclusions to be drawn. It was suggested earlier that ‘delving deeper into the particular also takes us closer to the universal...’ (Smith, 2004). It is possible, therefore, that the experience described herein contains an essence of the experiences of others in similar situations to Saskia. Stake (1998) also noted that case studies can be of value in refining theory and suggesting complexities for further investigation. The extent of this study’s findings in common with other studies reinforces some existing theories, yet the uniqueness and complexity of some of them leave a good deal of scope for future research.

6.5.2 The interview

Throughout the interview Saskia presented as an articulate, intelligent woman with considerable insight into her experience as a partner and ‘carer’ of a stroke survivor. Saskia can perhaps be considered the ultimate ‘self-reflexive agent’ (Smith, 1996). Her account was emotionally literate, with high levels of disclosure and honesty. She was able to convey a powerful sense of the pain, toil and drama she had experienced. Her observations and recall relating to events and their implications were remarkable in their breadth, depth and detail: these were subjects she had obviously considered and reflected upon at length. These needed little prompting during the interview, and even on occasions where it could be suggested I was interpreting her comments during the interview, she maintained a strong focus on her own narrative. Saskia mentioned that she had talked with various friends and family members and had seen a counsellor. It can therefore be assumed that she was articulate and coherent at least partly because she had already developed her understanding and insight as a result of those conversations.

6.5.3 The analysis method: the trustworthiness of the study

Data was analysed following adapted guidelines for conducting IPA, the process for which was described in section 6.2.4. IPA’s use was consonant with the aims of the research, ie to explore in detail the participant’s personal experience (Smith et al, 1999)

and the stance of the researcher. The approach is inherently interpretative: the words of the participant were analysed and condensed during the analysis process, and therefore influenced by my own perspective. I acknowledge that other interpretations of the same data could be made. However, it is hoped that the inclusion of personal information and a clear presentation of the research process and findings, all of which were audited to address issues of credibility and rigour (Miles and Huberman, 1994; Elliott et al, 1999), have enabled an understanding of how and why interpretations were made. This inclusion demonstrates my attention to reflexivity and therefore, to one aspect of trustworthiness. Also, by grounding the analysis in the data and supporting my interpretations with verbatim evidence from Saskia, the study demonstrated sensitivity to the data and ‘importance of fit’ (Henwood and Pidgeon, 1992; Yardley, 2000; Smith and Osborn, 2003).

As with my use of FM analysis for Study Two, my analysis for this study entailed systematic sifting through the data, the process of which I made explicit in the findings section. The combination of the flexibility of IPA’s method and the richness of Saskia’s account enabled me to immerse myself in the data to a greater degree than for Study Two. Certainly, my many readings of the transcript and lengthy journeys through the emerging themes did ‘throw up new insights’ (Smith and Osborn, 2003) about the data, which continued to develop up to and including writing this report. I was able to explore the data creatively and from many different angles, to the degree that it was also possible to link the findings to extant theoretical concepts while maintaining contact with Saskia’s original experience and context. IPA had me ‘under Saskia’s skin’, and often with a sense of living and breathing her experience.

6.5.4 Observations on perspective

The data and analysis of Saskia’s account was presented in chronological phases, ie life pre-stroke, Jim’s stroke, rescue mission, endurance and regeneration. However, Saskia spoke to me when she was living the ‘endurance’ phase. This means that this was the only phase being described at the time that it was being experienced. The prior phases were described, subject to recall, and, importantly, with the benefit (or prejudice) of hindsight. Similarly, the regeneration phase was a projection into an imagined future. These were Saskia’s memories of the past and visions of the future at a point in her life

where her perspective was stressed and she was confronting the absence of hope and meaning.

Smith (1994) suggested that people deal with major transitions in their lives by modifying their narratives to reflect self-enhancing accounts. This is termed 'self-reconstruction' and it is noted that there are discrepancies between contemporaneous and retrospective accounts of experience. It could be seen that Saskia's accounts of the past, the present and the future all maintained a sense of positive self-image, even when the events to which she referred challenged it. The implication is that the story may have been told differently if it had been told contemporaneously. For example, if told at the time of the rescue mission, Saskia may have said things that implied that her positive self-image was dependent on a 'successful rescue', ie a full recovery for Jim. However, when this recovery did not occur, her retrospective account emphasised Jim's inadequacies and implied his failure as opposed to hers. Saskia was able to maintain a self-enhancing thread throughout the phases that she described. It can be suggested that this theory even applies to her vision of a future when Jim has died and she is 'regenerated'. A longitudinal study of Saskia's experience to explore both contemporaneous and retrospective accounts would have been interesting. Such studies may be a valuable avenue for research with other partners.

Staying with the construction of Saskia's account, it is noted that this was Saskia's story about her life as Jim's partner, before and after his stroke. It is specifically centred on the perspective of Saskia, not Jim, and Saskia is the only story-teller. Researching Saskia's perspective was justified because of the need to understand more fully the experience of partners in her position. However, in looking specifically at the experience of the partner, it can be seen that this experience was intrinsically related to the PWA on two profound levels. First, Saskia's experience only existed in relation to Jim's stroke illness. If this did not exist, there would be no subject. Second, on listening to Saskia's story, it appeared to relate to Jim on every level. She talked at length about her relationship with Jim, about her observations of him. Even when she talked about herself, it was in relation to her struggle to come to terms with her life after Jim's stroke. The result is that this study says a lot about Saskia's experience and needs as a partner of a stroke survivor. It was not structured or meant to give Jim a voice or to understand his experience. It is acknowledged, though, that the needs of partners are inextricably linked to the needs of the PWA. It implies that future studies about the

experience of partners/carers and professional services for them need to be sensitive to this point.

6.6 Study conclusions

This study asked: ‘How does a partner perceive and describe her experience of living with a person with aphasia?’ In exploring this question, the following conclusions have been reached.

- 1 The most significant contribution this study has made to the body of knowledge about the experiences of partners of PWA is an increased understanding of the *complexity* of the phenomenon. In revealing that complexity, it also exposes the limits of current knowledge and suggests new avenues for clinical practice and research.
- 2 The partner studied described her experience as a difficult journey. It was a complicated process of accommodation and adaptation to her changed circumstances. The process was mediated by several factors:
 - Her experience related to different phases linked to life pre-stroke, stroke, rescue, endurance and regeneration. Each phase had a clear link to how she responded to and coped with the experience;
 - The process featured changing roles for Saskia, which were linked to her responding/coping experience and to her perception of her relationship with the PWA (her husband);
 - As phase, role and relationship shifted, so did Saskia’s self image. Her self image was directly related to her capacity to respond to the needs of her husband to cope with the changes in their life.
- 3 The study showed that aphasia impacted upon the couple’s communication. However, it was only a *part* of the experience revealed; while Saskia did refer to changes in her and Jim’s communication, she was far more absorbed by her notion of their changing relationship based on changing roles and self image.
- 4 Saskia’s ambiguity and ambivalence in relation to her experience were reflected in changes in her language and terminology in the different phases. This may

reveal a fundamental inadequacy of discourse and terminology to fit her experience. Most notably the term ‘carer’ was too rigid and therefore prescriptive about Saskia’s role and her relationship with her husband. It had a corrosive effect upon both Saskia’s and her husband’s sense of themselves as individuals and as a couple. Subject to further debate and search for even more meaningful terminology, there is a case for using the term ‘partner’. It is more able to accommodate the shifting roles and perceptions related to the complex transitions that need to be made following stroke. This term also retains and honours the central interaction of life pre-stroke and the dignity of both players. Partner is defined as a relationship of sharing and includes companionship. Just as importantly, it does not define the balance of power or ability. Partners (where one of whom has caring responsibilities) are invited to have an ongoing exchange about their respective contributions to the relationship. They are not irretrievably defined as people by the term attributed to them, as in ‘carer’ and ‘cared for’.

6.6.1 *Conclusions about methodology, further research and clinical practice*

- 1 This idiographic study has begun to answer the fundamental question of how partners cope with living with and caring for a PWA in the long term. The study looked at one case. I would argue that only the close examination of this individual could have produced the detailed exposition and theoretical contributions of the study. Though the study makes no claim about other partners living other experiences, it seems likely that equally complex processes take place for others. It may be valuable to employ a similar methodology with other partners of stroke survivors, PWA or other chronic illnesses, to see if similar or different processes occur. It may also be useful to explore partner accounts at different periods in their experience.

- 2 In providing knowledge about the complexity of one person’s experience, the study begins to provide professionals with a deeper understanding of partners’ perspectives, not just of aphasia itself. Developments in professional assessment of partners, and intervention for them, can be driven from this understanding. For example, it is suggested that the conclusions below will be valuable when

planning future intervention programmes based on the support and conversation training programmes described in Studies One and Two of this thesis.

- 3 Assessment and intervention for partners should take into account the complex and phased nature of life post-stroke and specifically address role, relationship and self image in these phases.
- 4 Professionals need to be sensitive to the terminology they use. It is suggested in point 4 of the previous section that the term ‘partners’ (one of whom has some caring responsibilities) may often be preferable to an over-reliance on the terms ‘carer’ and ‘cared for’. While it is acknowledged that better terminology may emerge from further consultation with service users and professionals, the essential point is about avoiding terms that provide a simplistic and prescriptive definition of a complex and uncertain relationship.
- 5 Aphasia therapists need to recognise when assessing and planning treatment that aphasia may not be the central or most pressing issue for some partnerships living with aphasia in the long term.

The contributions of this study and the previous two to the overall thesis are considered in the following chapter.

CHAPTER 7

THESIS CONCLUSIONS

In its statement about the requirements of PhD thesis, University College London (2002) noted that a thesis should ‘advance the study of the subject... represent a distinct and significant contribution to the subject, whether through the discovery of new knowledge, the connection of previously unrelated facts, the development of new theory, or the revision of older views’. Below I set out how this thesis has achieved those requirements. I provide a concluding summary of the studies, their links, strengths and areas for further research and clinical development.

This thesis comprises three related studies, each of which has at its heart the psychosocial experience of partners of people with aphasia. The thesis can be described as evolutionary on a range of levels. The second study evolved from the shortcomings of the first, and the third study was designed to explore in detail a particular aspect of the second. With each study, the methodology also evolved. It moved from studying the ‘group’ to the individual, and from researcher-led assessment to methods capable of capturing insider perspectives, ie from quantitative to qualitative data analysis. I would argue that each study built upon the other in terms of the appropriateness of methodology, depth of findings and contribution to the body of knowledge about the psychosocial effects of aphasia for partners of PWA. This means that the development of the conclusions were also part of this evolution and to an extent cumulative.

Study One utilised a quantitative yet idiographic measure to assess the psychosocial outcome of a group support programme and a group conversation training programme, using the PQRST (Mulhall, 1978). At the time of this early study, the only previous published attempts at using the measure to evaluate programme outcome had analysed quantitative data from a broad group perspective. This study provided similar broad analysis as a means of comparison with previous work, but it also went beyond the group to provide analysis at the level of the individual. The statistical analysis on individual data sets showed the results to be more complex than those revealed through the group analysis. The conclusion that four participants appeared to have benefited from the Support Programme and that two changed as a result of the Conversation Programme, provided a contribution to the small body of literature which provides and describes evidence for managing psychosocial difficulties of partners. The analysis highlighted patterns of change across the study, and facilitated some exploration of additional factors that may have influenced results, such as time living with aphasia. However, even at the individual level, significant data reduction was required to

facilitate analysis, meaning it was not possible to ascertain how each individual's different psychosocial issues changed. A significant contribution of the study therefore, was the conclusion that the quantitative PQRSST is limited in its ability to capture or monitor such a complex phenomenon as 'psychosocial change'. It adds weight to the existing opinion that the nuances of individual experience of both psychosocial life and participation in intervention cannot be reduced to numerical scores or even to a set of statements.

Study Two aimed to address the limitations of the method and findings of Study One, by exploring partners' own perspectives on factors within the content and process of the Support and Conversation Programmes that influenced participation in the programmes and psychosocial outcome. To achieve this, the 'Framework Method' (Ritchie and Spencer, 1994) was used to analyse semi-structured interviews with the participants. The result of this qualitative shift in methodology was the finding that *all* participants of the programmes experienced some psychosocial benefits of *both* programmes. Additionally, it exposed some negative effects that had not been accessible in the previous study. Importantly, the qualitative methodology was able to expose the mechanisms related to programme content and organisation, group and personal processes, and individual circumstances, that promoted or inhibited programme participation and psychosocial change. In discovering these, Study Two represents a distinct and significant advancement in knowledge about two specific group-work interventions for partners of PWA. It provides aphasia clinicians with a partner-centred framework for planning and evaluating the interventions, and has begun to provide a 'theory of therapy' for the interventions.

Study Two also contributes to some wider theoretical arenas. For example, it adds to the body of knowledge about the complex mechanisms of social comparison in group work and the effects of social comparison on individual coping strategies. It explicates the process and outcome of 'sharing' in a therapeutic environment, and links group and personal processes as influential in group participation and psychosocial change. The study also created avenues for useful future research. It suggested that the nature of the interactions between factors that influence programme participation and psychosocial change should be explored more fully, including those that began to be exposed in this study, such as the influence on candidacy for change of individual personality types, coping strategies and state of relationships. It pointed to the need to research

programmes for more homogenous groups of participants and those co-worked by professionals other than SLTs. Finally, it provided evidence that involving a previous research participant as a researcher is valuable.

The analysis method of Study Two enabled detailed exposition of the study themes. These were grounded in the participants' own perspectives and language and presented after rigorous attention to aspects of trustworthiness. The themes were predominantly about the partners' experiences of the interventions. However, aspects of the data suggested a need to return to the fundamental question of what psychosocial life is like for individual partners in the long term, outwith the context of intervention. This question required a methodology capable of exploring such phenomena to a depth that had not been achieved in the previous two studies. Hence, IPA (Smith 1995; 1996) was utilised in the third study of the thesis to examine in-depth interview data from one partner, about her perceptions of her experience of living with her husband with aphasia. Study Three therefore moved yet further along the insider perspective / qualitative methodology continuum than the previous study.

By using IPA's idiographic, inductive, phenomenological and interpretative approach to explore in detail just one set of rich and compelling interview data, Study Three makes the most significant theoretical contributions about the psychosocial experience of partners of PWA of the three studies. This methodology is therefore recommended for future research related to both psychosocial and intervention experience. The study provides new and trustworthy knowledge of what it is like to be a partner of a person with aphasia. It reveals the complex, phased journey of the partner's accommodation and adaptation to changing circumstances after her husband's stroke, in a way and in a depth not apparent in existing related research. It links the phases of life pre-stroke, stroke, rescue, endurance and regeneration with the processes of change in roles, relationship, self-image and mechanisms of coping. Importantly for aphasia therapists, it concludes that these changes, rather than aphasia itself, were central to the partner's experience. In moving away from the context of intervention, then, Study Three was actually able to contribute new findings that can be used to drive further research and improvements and developments in professional assessment and intervention. It can be hypothesised that there will be many different and diverse experiences amongst partners other than the partners featured herein, and that the needs of partners of PWA are likely to be as diverse as the differences in personality, relationships and culture throughout

society. Further studies that build the picture of complexity and diversity across different partners of stroke survivors or PWA are obviously required. However, the message from this thesis is that clinicians need to understand and provide intervention for the complexity of individual experience. This has implications for service delivery management. The notion that there is a 'one size fits all' approach to professional support for partners of PWA should be rejected. Rather, intervention for partners needs to be based on an assessment process that carefully considers phase, role, relationship and self-image, and needs to be fluid and responsive to change and diversity. This may mean that the support and conversation training programmes described in this thesis need to be further modified to suit the specific needs of individuals, and then evaluated.

The conclusion from Study Three, backed up by some of the findings of Studies One and Two, that aphasia is not necessarily the central issue for partners living with and caring for a PWA, may have implications for the SLT's role. There is a strong case for suggesting that clinical assessment and intervention developed from the work described herein should be multi-disciplinary. As well as SLTs, there would appear to be roles for professionals from psychology, counselling, nursing and social work. These professionals should be invited to make contributions to assessment tools, collaboration, consultation or co-work in clinical intervention in an individual or group-work setting, and to further research suggested by this thesis.

Study Three suggested additional avenues for further debate and research. The findings implied that the current and predominant 'carer' discourse and terminology is inadequate for capturing the shifting roles and complex transitions that couples experience following stroke. It was suggested that a term such as 'partner' is more able to accommodate the complexity and respect the diversity of people's experience as individuals and as a couple.

It was noted that the study was only partly based on the partner's contemporaneous account of her experience. Much of the theory that emerged was based on her retrospective accounts of earlier phases in her experience. It was suggested that these accounts may have described a different experience if they had been told contemporaneously, and that this discrepancy could be explained by her need to maintain a phased story that was self-enhancing. This theory could be tested by further

research that is longitudinal and takes contemporaneous as well as retrospective accounts at different phases of the partner's experience.

It was also concluded that the findings were entirely centred on the account of the partner of the PWA. It was acknowledged that this was very appropriate because it was her individual experience that was sought. However, it was also recognised that her experience was intrinsically linked to the experience of her husband after his stroke. It was therefore concluded that his account of his experience of her as a partner would add a valuable perspective to the findings. The voice of PWA in further research about their partners is needed both in terms of qualitative depth and increased understanding of the combined needs of both parties.

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Appendix 1A

Prompt sheet used during interview to identify issues for inclusion on PQRST

PQRST: prompt sheet

This questionnaire is to find out how you feel about certain things since your partner's stroke. To do this we need to write these feelings down. When we have thought about the feelings that are most important to you, we will write them down in such a way that we can qualify them with an adjective. For example, if you were to say: 'I am suffering from a feeling of tension', we would have to write down 'my feeling of tension is...'

When we have written down your feelings we can move on to the questionnaire.

As I said before, the questionnaire is to find you how you feel about certain things. There are no right or wrong answers. In each column of the answer sheet there are pairs of circles. To the right of the sheet are listed those things we want to know how you feel about. On the page to the left of the circles are pairs of adjective statements. Choose which of the two statements best describes how you feel about the topic specified on the right, and put an X in the circle next to it. If neither statement describes how you feel choose the one which comes closest. Make sure you choose one statement from each pair and repeat this all the way down the page, then turn over and follow the same procedure on the next page.

Do not spend long on any item. The whole questionnaire should only take a few minutes.

Prompt questions

What was it like immediately after the stroke?
How have things changed since the stroke?
What things are different now?
How do you feel about your situation since the stroke?
How do you feel about your partner's communication?
Has your relationship changed since the stroke?
Has your home life changed?
Has your social life changed?
How have your family coped since the stroke?

Appendix 1B

Written instructions for self-administration of the PQRST assessment

PQRST questionnaire: instructions

This questionnaire is to find out how you feel about certain things.

There are no right or wrong answers.

In each column of the answer sheet there are pairs of circles. To the right of the sheet are listed those things we want to know how you feel about. On the page to the left of the circles are pairs of statements.

Choose which of the two statements best describes how you feel about the topic specified on the right and put an X in the circle next to it. **If neither statement describes how you feel, choose the one which comes closest.**

Make sure you choose one statement from each pair and repeat this all the way down the page, then turn over and follow the same procedure on the following pages.

Do not spend long on any item. The whole questionnaire should only take a few minutes.

Appendix 1C
Completed PQRST assessment for one participant

Appendix 1D

Individual participants' sets of PQRS statements

Participant 1: Judith

- 1 My worry about J having another stroke
- 2 My concern at J not being with me if he has another stroke
- 3 I miss getting out socially
- 4 The disappointment I feel at visiting our family less
- 5 My level of worry about J's diet
- 6 My level of frustration at having to be face to face for conversations
- 7 My frustration that J can't understand me and I have to repeat myself

Participant 2: Fatima

- 1 My level of worry about B's health
- 2 The sadness I feel about what has happened to B
- 3 My worry about coping in the future
- 4 The scared feelings I have about learning how things work in the house
- 5 The nervousness I feel about taking responsibility in the house

Participant 3: Lauren

- 1 The loss I feel about the closeness of our atunement
- 2 My anger at people 'talking down' to B
- 3 My embarrassment at people 'talking down' to B
- 4 My humiliation at people 'talking down' to B
- 5 My irritation at the loss of 'natural' communication and the pressure to treat B as 'precious'
- 6 My anger and frustration at not getting the professional counselling and support I need
- 7 My tension that builds up about clarifying domestic decisions
- 8 The pain at the loss of support I received from B before his stroke
- 9 The effect of the stress surrounding B's stroke on my health
- 10 My annoyance at the arrogance and insensitivity of the nursing staff

Participant 4: Tina

- 1 My degree of social isolation
- 2 My need for constructive counselling
- 3 My need for an outlet for stress
- 4 The negative feelings I have about being taken for granted
- 5 My sadness at a lack of a support system
- 6 My lack of freedom to pursue my own interests
- 7 My hurt that our friends don't keep in touch

Appendix 1D cont/d

Participant 5: Kurt

- 1 My difficulty in adjusting to the role change
- 2 My difficulty finding balance in household activities
- 3 My knowledge of how to cope after stroke
- 4 My frustration when M doesn't understand me
- 5 My dissatisfaction with our relationship
- 6 My disappointment at having less holidays in our retirement
- 7 My feeling of isolation and neglect
- 8 My anger at the lack of counselling and professional support

Participant 6: Carole

- 1 My frustration at always having to plan to go out
- 2 My upset at not being able to go away like we used to
- 3 My anger at N having a stroke
- 4 My disappointment at losing our friends
- 5 My feeling of isolation
- 6 My worry at N being left alone
- 7 My annoyance at being depended on
- 8 My feelings of missing the companionship of working

Participant 7: Ursula

- 1 My panic when I can't understand what J is saying
- 2 My upset at other people's attitudes towards J and his stroke
- 3 My worry for J that his speech won't get better
- 4 My worry about explaining J's difficulties to strangers
- 5 My worry when other people can't understand J

Participant 8: Amy

- 1 My frustration that we can't get up and do what we want
- 2 My sadness that I can't exercise the dogs which does us all good
- 3 My anger that P has had a stroke
- 4 My sadness that our plans for our retirement won't be achieved
- 5 My annoyance that our friends haven't coped with P's difficulties
- 6 My sadness that P can't do his hobbies any more
- 7 My frustration that this has happened when we are still young
- 8 My sadness and frustration that P can't take me out any more
- 9 My hatred of the extra responsibilities I have for the house

Appendix 1D cont/d

Participant 9: Vera

- 1 My disappointment that I have had to give up my college course
- 2 My anger that I don't have time to myself
- 3 My bitterness that I'm not achieving anything for myself
- 4 My resentment that we don't have the money to do things
- 5 My anger that I can't go anywhere on my own
- 6 My annoyance that B doesn't help me around the house
- 7 My disappointment in myself that I eat too much
- 8 My hurt that there's nothing to look forward to to look nice for
- 9 My annoyance that I can't plan to do anything
- 10 My upset that I see my family less

Participant 10: Gwen

- 1 My worry that I don't get the right message when M is talking
- 2 My worry about dealing with the finances
- 3 I miss having a conversation with M
- 4 My embarrassment at relying on other people for transport
- 5 My sadness that we can't go shopping together
- 6 My depression that I have to go to church on my own
- 7 My sadness that we can't go on the long-haul holiday we planned
- 8 The strain of having to think for M

Participant 11: Jenny

- 1 I miss my dad's conversation
- 2 My anger at the lack of support from hospital staff
- 3 The monotony of doing the same thing every day
- 4 My disappointment at the lack of support from hospital staff
- 5 My feeling of guilt at not giving attention to the children while I'm with dad
- 6 My worry at dad not being able to tell me if something was wrong

Participant 12: Denise

- 1 My feelings of guilt at not taking Dad out with me all the time
- 2 The restrictions on my freedom to go away
- 3 My worry about dad's health and safety when he's alone
- 4 My dread of our family 'splitting up' if anything happens to dad
- 5 My tiredness at caring for dad
- 6 My worry that life is passing me by

Appendix 2A

CWC Project post-programme interview topic guide

Programme content / design (brief)

Which sessions were most / least important to you? (show overview of programmes)

How easy or difficult was it to understand what the therapist was talking about in the sessions?

How did you feel about doing the activities in the sessions?

What did you think about the communication handbook?

Is there any information you would like to have received but didn't?

What do you feel about: how long each session lasted?
 the number of sessions?
 timing of the sessions? (did they come at the best time for you
 after your partner's stroke or not)

What do you think about recording your conversations on video?

How useful was it for you to see yourselves on video during the sessions?

How does this sort of therapy compare with what you have received in the past?

Factors affecting participation and change

Do you think you got anything out of going to the group?

Was there anything that stopped you making the most of the sessions?

Is there anything you would have liked to have covered or discussed in the programmes but didn't?

- issues about communication
- issues about life in general
- issues about your relationship with your partner
- issues about your relationships with other people, eg family/friends

Do you feel how you talk or communicate with your partner has changed in any way?

Do you feel your partner's communication has changed in any way?

Do you feel you / your partner have changed in any way because of the programme, for other reasons?

Do you feel the group offered you support or not?

Before the group, what support did you have?

Can you make any suggestions as to how the programmes could be improved?

Appendix 2B

Extract of an interview transcript (Tina)

Transcript for: Tina (T), interviewed by Lauren (L) on 20/11/97

Transcription completed: 23/11/97

Code	No	?	Transcription	Comment
	1	L	When I said that we want to get some comments about,, good bits and bad bits they're not total judgements about it	
	2	T	no=	
	3	L	=but just how it struck you, and the useful thing is if we take,, first of all look at, the group sessions when we were all sat here	
	4	T	mm	
	5	L	and then, ehm, perhaps we could talk about what it was like when you and K were thinking about the course and talking about it, so it doesn't have to be a terrifically,, complicated, uh heh, way of looking at and I was wondering what came, to mind when we were thinking about the course or perhaps when you first started	
	6	T	well sort of thinking about, the before and after, perhaps that's one way of doing it	
	7	L	mm hmm, mm	
	8	T	yes I think ehm,,, the first sessions,, were,, useful in that I did, learn more about the actual-what went-what came from which bit of the <u>brain</u> =	
	9	L	=right, so it was <u>explaining</u> about [(syll),, mm hmm?,, yeah]	
	10	T	[yes,, the technical, part] there,, uhm, the ac-the second,, uhm,,, <u>stage</u> of the course I suppose the second group of eight sessions,,, uh:, yes there were things of value there I think the	
	11	L	mm	
	12	T	eh, well obviously the-the sort of technical structure of conversation=	
	13	L	=mm, 'cause they were, quite handy <u>tips</u> in one way weren't they, that you could use,, (was it something) like that for you?	
	14	T	yes I think I did get,, if we get <u>stuck</u> ,, then something comes to mind,, I wouldn't say eh that I sort of set out when I'm talking to K,, with something in mind, it's if,, we- we encounter a-a sort of stopping point,, then I can draw on something I've learnt I think	

Appendix 2B cont/d

Code	No	?	Transcription	Comment
	15	L	mm,,, so you use it for first aid (or some[thing syll syll])	
	16	T	[yes, I think-] I think that would be a v- a valid comment yes, yes,,, uhm,, as far as the other- well	
	17	L	mm,, mm	
	18	T	obviously I think it was, I didn't find,,, the em, talking to other stroke, <u>carers</u> as it were,, to be as a negative an experience as I was afraid	
	19	L	oh you were actually, before you started thought it might be awful	
	20	T	I thought [it-]	
	21	L	[what] did you think might happen	
	22	T	well because I'd had a negative experience before [in the very early] stages	
	23	L	[oh right]	
	24	T	when I was,, told to go to this stroke carers group [which no longer]	
	25	L	[oh (right)]	
	26	T	exists,, and I was simply frightened out of my <u>wits</u> actually because K was- it was within a few days,, or weeks, he was still in hospital,, and all these terrible things that,, were going on because the- the carers there there were- they were,, I mean, even, there was one, woman whose husband, well, who's like B, physically he wasn't affected,, but it wasn't really his <u>speech</u> , mentally he was incapable	
	27	L	mm	
	28	T	,, and eh, it it had- I don't know what the phrase would be but I mean if if she took him shopping she had to hang on to his coat,, otherwise he wandered off	
	29	L	,,did she tell you a lot about this? or [(you were) <u>seeing her</u>]? or-	
	30	T	[<u>yes</u>]	
	31	T	=well no they were telling us about this and then another man had a wife who was very very,, badly affected and,, you know (syll syll) talking about yes yes and you know	
	32	L	so you had a bad experience heh heh (syll syll to st(h)art with)	
	33	T	while K was still in hospital I thought <u>no</u> this is the last [thing] I want,,	
	34	L	[mm]	

Appendix 2C

Transcription notation symbols

over[lap] [over]lap	square brackets between adjacent lines of concurrent speech denote the start and end of overlapping talk
(syll syll)	unclear speech rendered as approximations to number of syllables
(unintelligible)	unclear speech, often a lengthy segment from which it is not possible to judge number of syllables
(word)	material within brackets represents the transcriber's guess at an unclear part of the tape
.hh, hh	speaker's in-breath and out-breath respectively
w(h)ord	(h) denotes laughter within words
cu-	a dash denotes a sharp cut-off of a prior word or sound
lo:ng	a colon shows that the speaker has stretched the preceding letter or sound
run= =on	equals signs link material which runs on
<u>under</u>	underlining indicates emphasis
°quiet°	speech which is noticeably quieter than surrounding talk
>fast< <slow>	'greater than' and 'less than' signs indicate that the talk they encompass is noticeably quicker or slower than the surrounding talk
yes?	a questions mark indicates rising intonation, not necessarily a question
,	very short pause
„	short pause
„„	long pause
„„„	very long pause

Appendix 2D

Thematic index developed from transcripts

(P = partner, A = person with aphasia)

1) Personal circumstances	5.2 other family
1.1 time post onset of stroke	5.3 friends
1.2 P & A's relationship	5.4 work colleagues
1.3 character / personality	5.0 other informal contacts
1.4 work / education	6) Personal response to aphasia
1.5 daily / household routine	6.1 P's perceptions of knowledge of stroke / aphasia
1.6 activities / leisure	6.2 P's reaction to stroke / aphasia
1.7 finance	6.0 other
1.8 transport	7) Programme design / content
1.0 other	7.1 referral to programme
2) Stroke (other than communication)	7.2 expectations of / personal aims for programme
2.1 events leading to stroke / cause	7.3 general organisation (timing of the group (after stroke) / time of day / length / number / location / group size / travelling
2.2 experience of stroke event	7.4 videos
2.3 physical effects	7.5 content / subject areas
2.4 rehab	7.6 verbal and written material / information
2.5 psychological effects (including cognition / behaviour)	7.7 activities / exercises / role play
2.0 other	7.8 therapist's contributions
3) Communication	7.0 other
3.1 before stroke	8) Group dynamics / processes
3.2 immediately after stroke	8.1 relationship with other members
3.3 before programme	8.2 perceptions of members' behaviour in sessions
3.4 since programme	8.3 perceptions of other member's relationships / partners
3.5 therapy (past/future)	8.4 relationship with therapist
3.0 other	8.5 feelings during group
4) Professional / services response to aphasia	8.6 absence from / leaving programme
4.1 health services	8.7 evaluation of programme
4.2 social services	8.8 A's interest in programme
4.3 voluntary organisations and self-help groups	8.0 other
4.4 information (from all categories)	9) Other
4.0 other services / agencies	
5) Social network response to aphasia	
5.1 partner and those living in household	

Appendix 2E

Indexing applied to Tina's transcript

Code	No	?	Transcription	Comment
	1	L	When I said that we want to get some comments about,, good bits and bad bits they're not total judgements about it	
	2	T	no=	
	3	L	=but just how it struck you, and the useful thing is if we take,, first of all look at, the group sessions when we were all sat here	
	4	T	mm	
	5	L	and then, ehm, perhaps we could talk about what it was like when you and K were thinking about the course and talking about it, so it doesn't have to be a terrifically,, complicated, uh heh, way of looking at and I was wondering what came, to mind when we were thinking about the course or perhaps when you first started	
	6	T	well sort of thinking about, the before and after, perhaps that's one way of doing it	
	7	L	mm hmm, mm	
7.5 8.7	8	T	yes I think ehm,,, the first sessions,, were,, useful in that I did, learn more about the actual-what went-what came from which bit of the <u>brain</u> =	
	9	L	=right, so it was <u>explaining</u> about [(syll),, mm hmm?,, yeah]	
7.5 8.7	10	T	[yes,, the technical, part] there,, uhm, the ac-the second,, uhm,,, <u>stage</u> of the course I suppose the second group of eight sessions,, uh:, yes there were things of value there I think the	liked 'technicalities'
	11	L	mm	
7.5	12	T	eh, well obviously the-the sort of technical structure of conversation=	
	13	L	=mm, 'cause they were, quite handy <u>tips</u> in one way weren't they, that you could use,, (was it something) like that for you?	L shaping T's response?
3.4	14	T	yes I think I did get,, if we get <u>stuck</u> ,, then something comes to mind,, I wouldn't say eh that I sort of set out when I'm talking to K,, with something in mind, it's if,, we- we encounter a-a-a sort of stopping point,, then I can draw on something I've learnt I think	learnt strategies for communication breakdown

Appendix 2E cont/d

Code	No	?	Transcription	Comment
	15	L	mm,,, so you use it for first aid (or some[thing syll syll])	
	16	T	[yes, I think-] I think that would be a v- a valid comment yes, yes,,, uhm,, as far as the other- well	
	17	L	mm,, mm	
7.2 7.5	18	T	obviously I think it was, I didn't find,,, the em, talking to other stroke, <u>carers</u> as it were,, to be as a negative an experience as I was afraid	negative expectations of programme based on past experience
	19	L	oh you were actually, before you started thought it might be awful	
	20	T	I thought [it-]	
	21	L	[what] did you think might happen	
4.3	22	T	well because I'd had a negative experience before [in the very early] stages	
	23	L	[oh right]	
4.3	24	T	when I was,, told to go to this stroke carers group [which no longer]	
	25	L	[oh (right)]	
4.3 (2.2) 6.2 9 6.2 (all to turn 33)	26	T	Exists,, and I was simply frightened out of my <u>wits</u> actually because K was- it was within a few days,, or weeks, he was still in hospital,, and all these terrible things that,, were going on because the- the carers there there were- they were,, I mean, even, there was one, woman whose husband, well, who's like B, physically he wasn't affected,, but it wasn't really his <u>speech</u> , mentally he was incapable	early days comparison with others
	27	L	Mm	
	28	T	,, and eh, it it had- I don't know what the phrase would be but I mean if if she took him shopping she had to hang on to his coat,, otherwise he wandered off	
	29	L	,,did she tell you a lot about this? or [(you were] <u>seeing</u> her)? or-	
	30	T	[yes]	
	31	T	=well no they were telling us about this and then another man had a wife who was very very,, badly affected and,, you know (syll syll) talking about yes yes and you know	
	32	L	so you had a bad experience heh heh (syll syll to st(h)art with)	
	33	T	While K was still in hospital I thought <u>no</u> this is the last [thing] I want,,	
	34	L	[mm]	

Appendix 2F

Chart headings and subheadings

<p>Chart 1: Perceptions of life before stroke</p> <ul style="list-style-type: none"> a) P & A's relationship b) character/personality c) work/education d) daily/household routine e) activities/leisure/interests f) contact with family g) contact with friends h) other social contact i) other <p>Chart 2: Perceptions of stroke (other than communication); its impact on psychosocial life in the short and long term</p> <ul style="list-style-type: none"> a) events leading to stroke/cause b) experience of stroke event c) physical effects d) psychological effects (including cognition/behaviour/character/personality) e) personal response to stroke/ knowledge of stroke f) services response (including medical/slt/other pams/social work/services) <ul style="list-style-type: none"> i) contact with services ii) evaluation of services g) family response h) friends response i) other contacts response j) impact on P & A's relationship k) impact on work/education l) effects on daily/household routine m) impact on activities/leisure/interests n) other <p>Chart 3: Perceptions of the programme: expectations; perceptions of what happened during programme and its impact; evaluation</p> <ul style="list-style-type: none"> a) perceptions of purpose/nature of programme b) expectations of programme c) anxieties and concerns: before/during/after sessions d) perceptions of own behaviours/feelings during sessions e) perceptions of other members' behaviours/feelings during sessions 	<ul style="list-style-type: none"> f) perceptions of other members: commonality/differences/other g) perceptions of therapist h) perceptions of A's involvement in programme i) perceptions of reasons for absence from/leaving programme j) evaluation of programme design and organisation k) evaluation of programme content/information l) changes in communication after programme (summary)* m) changes in relationship after programme* n) changes in psychosocial status after programme (including psychological status, work/education, daily routine, activities/leisure/interests)* o) changes in personal response to/knowledge of stroke/aphasia after programme* p) changes in family and social life after programme: participation/exclusion* q) other <p>Chart 4: Perceptions of communication</p> <ul style="list-style-type: none"> a) P's and/or A's linguistic skills (before stroke, short term after stroke, longer term after stroke) b) P & A's pattern/style of communication (before stroke, short term after stroke, longer term after stroke) c) A's pattern/style of communication with people other than P (before stroke, short term after stroke, longer term after stroke) d) changes in P's and/or A's linguistic skills/communication strategies since programme* e) changes in P's and/or A's pattern/style of communication since programme* f) changes in A's and/or P's pattern/style of communication with other people since programme* g) other <p><i>* on chart, changes attributable to mechanisms other than programme are underscored</i></p>
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Appendix 2G

Extract from Chart 3 showing subheadings a) to f) for Tina

Chart 3: Perceptions of the programme: expectations; perceptions of what happened during programme and its impact; evaluation			
Partner	a) perceptions of purpose / nature of programme	b) expectations of programme	c) anxieties and concerns: before/during/after sessions
Tina Age 60 4.9 yrs post-stroke	<i>Assumed it was something that I had to do, when I was communicating with Ken, it wasn't a two-way course</i> 347	expected that it would be a negative experience 18-33 →	had been to carers group in first few weeks after K's stroke while he was still in hospital - <i>frightened out of wits</i> by descriptions of others' experiences/terrible outcomes 18-33
Partner	d) perceptions of own behaviours/feelings during sessions	e) perceptions of other members' behaviours/feelings during sessions	f) perceptions of other members': commonality/differences/other
Tina	Wanted to know that other people share the same sort of problems 63, but when saw videos of people with worse problems felt <i>not at the bottom of the heap</i> 69 <i>Interested in Kurt's communication style – not irritating and felt he shouldn't be expected to change at his age</i> 139-155 <i>Felt envious about things that people could do and that we couldn't do</i> 159	Nothing said	Reinforcing to share others' experiences but felt worse off than other members – <i>more limited a life-style</i> 37-41

Appendix 2G cont/d

Key to charts

[]	items between square brackets are those that have been shaped in some way by the interviewer, eg a leading question, a statement of what she feels the interviewee has meant etc.
< >	From interviewer's comments/notes to researcher after interview
()	comments included from researcher's programme session notes, not the interview itself
{ }	researcher's comments/notes/observations either from the interview data or from assessment/therapy sessions
129	turn number on transcript
<u>145</u>	potential quote to capture essence of meaning
<i>italic</i>	interviewee's own language
<u>underscored words</u>	changes reported by interviewee not attributable to programme
?	unsure about what follows

PWA – person with aphasia

P - partner

Appendix 2H

Lauren's disclosures and evaluations of the programme, their context and impact

Lauren's disclosure/evaluation	Context in which occurred	Impact of disclosure on participant
Disclosures about self		
Has felt murderous and suicidal at times	During discussion initiated by Kurt about feelings of stress/uncertainty re coping with his wife's mood changes since stroke	Kurt talked further about his own feelings
Feels loss of husband as he was pre-stroke: misses sharing 'equal ways' with him	As part of question in response to Carole's discussion of her husband returning more to old self and resulting decrease in dependence	Carole discussed further their pre- and post-stroke roles
Has needed to talk about grieving for the husband she's lost	Recognition of shared experience in response to discussion led by Amy about grieving for loss of 'pre-stroke husband'	Amy moved discussion on to comparison of other group members' experiences related to this
Realised that dream of retirement was not going to come true after husband's stroke	In response to Gwen's discussion about her own realisation of her and her husband's situation	Further disclosure by Gwen
Disclosures about her husband		
The nature of his linguistic impairments	In response to Jenny's discussion of her father's greater abilities with numbers than words post-stroke	Not taken up by Jenny
Sees 'improvements' in him every day despite being five years post-stroke	In response to Amy's introduction of smashed dreams for retirement due to her husband's impairments	Led to Amy introducing discussion about improvement noted in her husband
	In response to Denise's statement about hope she felt when recognising improvements in her father	Denise continued discussion
	In response to Vera's discussion about small improvements noted in her husband	Vera continued discussion

Appendix 2H cont/d

Lauren's disclosure/evaluation	Context in which occurred	Impact of disclosure on participant
Evaluation of the programmes		
Felt she and other group members were <i>pioneers</i> of the programme's approach (so was excited and 'dead keen to go on it')	During discussion with Kurt about workings of project In response to Vera's discussion of her expectations of programme	Discussion continued by Kurt Vera gave her opinion of the programme
Felt there was a lot of information in each session, which perhaps left insufficient time for people to discuss their problems: enjoyed sharing experiences and feelings. Felt important that course offers time to talk about problems	In response to Gwen's recommendation that course could be improved by beginning with the SP rather than the CP	Gwen continued discussion
Appreciated programmes as prior to them 'didn't know anything about aphasia, felt upset, with no-one to talk to, and had a lot to learn'	In response to Fatima's descriptions of similar feelings and experiences prior to course	Agreed by Fatima
'Enjoyed the praise' when viewing video clips in sessions, 'though there wasn't a lot of it'	In response to Tina's discussion of benefits of viewing recorded conversations	Discussion continued by Tina
Stated that husband 'only really improved when I went to Sarah's course'	During discussion with Fatima about improvements in her husband's language	Discussion continued by Fatima

Appendix 2I

Summary of individual responses about making and observing videos of conversation and doing role-plays

	Tina	Carole	Kurt	Judith	Fatima	Gwen	Ursula	Vera	Jenny	Denise	Amy
Recording conversation onto video ✓ = recording representative of everyday conversation X = not representative	X	X	✓	✓	✓	✓	✓	✓	✓	✓	✓
Observing video taped conversations in sessions ✓ = useful for highlighting patterns X = not useful	✓	X	✓	✓	✓	✓	✓	✓	X	✓	✓
Doing role plays ✓ = enjoyed X = did not enjoy	✓	X	✓	X	✓	✓	X	X	X	X	X
Value of role plays for raising awareness ✓ = valuable X = not valuable	✓	X	X	✓	X	✓	✓	X	✓	X	X

Appendix 2J

Themed summary of the range of factors that promoted and/or inhibited participation and change

Factors related to content / organisation affecting participation and change (* denotes and/or affecting attendance)				
Factor	Promoted participation	Promoted change	Inhibited participation	Inhibited change
Information provided in SP	<ul style="list-style-type: none"> - encouraged reflection/personalisation – led to sharing views - interest in technicalities and different aspects of stroke - easy to understand - information clearly delivered 	<ul style="list-style-type: none"> - increased knowledge of stroke and aphasia - decreased anxiety about PWA's safety - increased confidence in how to deal with future stroke 	<ul style="list-style-type: none"> - information too academic - nature of information created anxiety re possible future effects stroke - challenged strategy of avoiding loss* 	<ul style="list-style-type: none"> - focus on information prevented learning of practical skills
Information provided in CP	<ul style="list-style-type: none"> - encouraged reflection/personalisation – led to sharing views - interest in technical aspects of conversation - easy to understand - information clearly delivered 	<ul style="list-style-type: none"> - increased awareness of PWA's aphasic difficulties - increased awareness of own/joint communication style or patterns - changed communication through new strategies learned & reduced communicative tension - new/reinforced strategies for communication breakdown - PWA's increased confidence/competence in communicating with partner/others - hope for future change 		<ul style="list-style-type: none"> - suggested communication strategies inappropriate or unacceptable

Appendix 2J cont/d

Factor	Promoted participation	Promoted change	Inhibited participation	Inhibited change
Recording / observing videotapes of conversation	- observation useful to illustrate successful communication and areas for change	- video captured natural every-day conversation - observation reinforced positive strategies and created actual change - promoted comparison process with positive outcome	- recording process stressful - observing self on video unpleasant - promoted comparison process with negative outcome	- video did not capture natural every-day conversation
Role plays	- enjoyed doing them	- increased awareness of PWA's difficulties	- did not enjoy doing them - not explained sufficiently - too soon into programme	- not representative of real life
Timing of programmes post-stroke		- programmes considered to have come at right time		- information given in SP already learned in period between stroke and programme - needed earlier to prevent psychosocial suffering - CP too late to change the communication habits (perceived as successful) developed between stroke and programme
Additional general organisation issues	- therapist's information-giving style and demeanour - participants' relationship with the therapist - programme not negative experience expected	- advice/ideas/strategies from therapist	- programme did not meet expectations* - 16 sessions a hefty commitment - care for PWA difficult - travel to venue difficult - number/mix in group - session/programme structure	

Appendix 2J cont/d

Factors related to individual circumstances (* denotes and/or affecting attendance)				
Factor	Promoted participation	Promoted change	Inhibited participation	Inhibited change
Everyday life			- Anxiety about leaving PWA* - needing to organise events at home/for PWA*	- volume of daily duties prevents making changes to help self
PWA's reactions to the project / their spouse		- partner sharing discussion of feelings with PWA = a change in relationship - partner's attendance at group perceived by PWA as interest promotes PWA's improvement	- PWA's negative response to partner's involvement	- PWA's disinterest in course / negative response to strategies introduced by partner (<i>due to feeling excluded, strategies undermining competence</i>)
Pre-stroke relationship / communication patterns				- negative pre-stroke relationship / communication
Factors related to group and personal processes (* denotes and/or affecting attendance)				
Social comparison	- promoted sharing and discussion of experiences, feelings, ideas	comparison process resulted in: - recognition of shared experiences / feelings, normalisation, validation, new ideas for coping, new friendship - feeling more positive about own situation (created hope for relationship, thankfulness, empathy towards other members, drive for creating psychosocial change) - feeling more negative about own situation (created envy, depression) - recognition of / unwanted challenge to personal response	comparison process resulted in: - feeling negative about own situation* - comparison process unexpected or upsetting* - feeling that being judged by fellow group members perceived as different to self	

* *Italics indicate uncertainty about impact in data*

Appendix 2J cont/d

Factor	Promoted participation	Promoted change	Inhibited participation	Inhibited change
Sharing	- promoted discussion of personal experiences, feelings, ideas	- learnt new ideas and skills for coping and communicating - increased awareness of others - perception of decreased isolation - forming of new friendships - actual psychosocial change realised (benefits for both partner & PWA) - hope for psychosocial change	- sharing problems unwanted or unexpected *	
Dominant group member			prevented others from listening/talking; irritating*	

Appendix 2K

Summary of changes perceived by each participant as a result of the SP and CP and suggested reasons for no change

Partner	Changes perceived as a result of SP	Changes perceived as a result of CP
Judith	↑ knowledge for dealing with stroke through programme content = ↓ anxiety = both benefited; developed friendship with Fatima	↑ understanding of PWA's difficulties; learned and carried out practical strategies to create communication change = ↓ tension; less demanding of PWA; PWA not needing SLT by end of programme
Fatima	enjoyed sharing experiences & problems; ↑ knowledge through programme content and sharing = ↓ anxiety re dealing with another stroke; shared info with PWA	↑ awareness of conversation patterns; learnt strategies to give PWA chance to contribute more = actual communication change = changed relationship
Tina	reinforced by sharing experiences; ↓ isolation; felt worse off than others but 'not bottom heap'; enjoyed learning more about stroke & aphasia	↑ awareness of communication; new strategies for communication breakdown but no actual conversation change - managing well prior to programme & too late to alter habits; enjoyed technicalities
Kurt	comparisons and sharing with others gave relief and validation; ↓ sense of isolation; actual psychosocial change after discussion in group: holiday (benefits to both); daily duties inhibit changes to help self	↑ awareness of communication; new practical strategies for communicating with PWA, tried to implement but change inhibited by PWA's reactions
Carole	enjoyed sharing problems: validated own thoughts, ↓ isolation; empathy for others; new ideas for coping; actual psychosocial change: PWA's scooter = PWA's independence = ↓ care-giving = roles reverting to previous	upset by recording & observing conversation video; ↑ awareness of communication but no actual conversation change – managing well prior to programme & too late to alter habits; PWA not willing to use suggested strategies
Ursula	alarmed by info re stroke; comparison process = feeling more positive about own situation & affinity with Gwen, but anxious about judgement by others; sharing problems = reduced isolation, validation	info resulted in feeling less confident in own skills at times but ↑ awareness of communication and PWA's difficulties; new strategies to enable PWA to contribute more to conversation; less worried as feels PWA is improving
Amy	busy at home; sharing problems 'rubbed in' losses (not expected); preferred to be at home with PWA: all influenced irregular attendance; suggested course as whole gave more fighting determination to help self and PWA	comparison resulted in feeling more positive about self and PWA, uncomfortable sharing problems; ↑ awareness of own communication; ?improvements in PWA's communication
Vera	opportunity to unburden self; ↓ isolation; developed positive relationship with some members; ↑ knowledge of stroke/aphasia from content & others; recognised relationship as more negative than others, ?but increased sense of hope; daily duties inhibit changes to help self	↑ knowledge of own conversation style, patterns & PWA's impairments; ↓ need to retaliate to PWA's outbursts; learned new strategies which attempted to use though pre-stroke communication & relationship patterns inhibited change; ?strategies possibly highlighted PWA's non-competence; noticed small improvements in PWA, created sense of hope: 'doing better'

Appendix 2K cont/d

Gwen	not applicable	comparison with others resulted in recognition of impact of stroke/aphasia, challenge to response and feeling worse off than others: depressed; irritated and upset by another group member's behaviour: left study
Jenny	comparison process = feeling more positive about own situation; sharing = new ideas for coping & feeling less isolated; recognised space & help given to Vera: made positive contribution to group;	↑ knowledge of own conversation pattern & strategies for communication breakdown, but no actual change in patterns: happy with those developed prior to programme & too late to change; enjoyed learning technical aspects
Denise	↑ knowledge of aphasia related to PWA; comparison process = feeling more positive about own situation; sharing = new ideas for coping & empathy with others: less isolated; forged friendship;	↑ knowledge of own conversation pattern but no actual changes in conversation with PWA – programme too late to change habits that both happy with; sharing = recognition of and delight at PWA's retained skills

Appendix 3A

Aphasia Disability Questionnaire completed by Saskia about Jim

Appendix 3B

Interview topic guide for Study Three

Research question: How do partners perceive and describe their experience of living with a person with aphasia?

I am going to break the interview into three broad sections. First I'll ask you to give me a brief history of your husband's stroke. Second, I'll ask you to tell me in more depth about your roles, relationship and identity. After that we'll talk in depth about how you have coped with life since your husband's stroke. All your answers will be treated in the strictest confidence. If there are any questions that you do not wish to answer or if you want to stop at any time, please say so.

A Personal circumstances (brief)

- 1 Can you briefly describe to me the history of your husband's (A's) stroke and aphasia?

prompt:

when, where, circumstances

- 2 What do you see as the main effects of the stroke on A?

prompt:

eg physical, communication, mental

B Roles/relationships/identity (brief for husband, depth for wife)

- 3 Can you briefly describe how A's stroke and its effects have impacted on his life?

prompts:

how has A's stroke affected him the most?

work

household routine/roles

activities/leisure

support networks

life goals

- 4 Can you tell me how he feels about changes to his life since his stroke, and describe any changes to those feelings over time?

prompt:

has he ever said how he's felt about how things are since his stroke?

eg frustrated, or maybe even happy, about, say, giving up work

IN DEPTH FROM HERE

- 5 Can you describe how A's stroke has impacted on your own life?

prompts:

how has A's stroke and aphasia affected you the most?

work

household routine/roles

activities/leisure

support networks

life goals

Appendix 3B cont/d

- 6 Can you tell me how you feel about changes to your own life since A's stroke, and describe any changes to those feelings over time?
prompt:
some partners have described different feelings about changes, eg some have said they have felt angry/frustrated at, say, having to give up work., others have been happier because they spend more time with their husband
- 7 Can you tell me about your role as A's carer?
prompts:
What do you have to do for him that you didn't used to?
eg bathing/dressing/feeding
- 8 Have changes to your and A's life and your role as A's carer affected your relationship together? If so, how?
prompts:
have they made a difference in how you see yourself as a couple?
have there been any changes in communication patterns, how you get on, your sex life?
- 9 Can you tell me how you feel about any changes to your relationship, and describe any changes to those feelings over time?
- 10 How would you describe A as a person, *both before and after his stroke*?
prompts:
what sort of a person was/is he; most important characteristics: happy, moody, nervy, laid back?
what do you put any changes in character down to?
how do you feel about any changes?
- 11 How would you describe yourself as a person?
prompts:
what sort of a person were/are you; most important characteristics: happy, moody, nervy, laid back?
- 12 Has living with and caring for A since his stroke made a difference to how you see yourself?
prompts:
if so, how do you see yourself now as different to before his stroke?
how would you say you have changed?
what do you put any changes in character down to?
how do you feel about any changes?
- 13 How do others see you/your relationship together (before and after stroke)?

Appendix 3B cont/d

C Coping

- 14 How much do you think about your own self/needs?

prompt:

do you think about or do anything to help yourself?

I want to find out as much as I can about how you have coped with living with a person with aphasia on a day to day basis, starting from when he first had his stroke through to today...

- 15 Can you describe how you felt when the stroke first happened?

prompt:

shock, angry, automatic pilot

- 16 How did you deal with the stroke when it first happened?

prompt:

did you have particular strategies for helping you?, ways of coping (practical, mental)

- 17 What about as time went on?

prompts:

eg, when he was in hospital)

when he came home)

in the first six months)

in the first year...

did you have any strategies

to help you cope?

(practical, mental)

- 18 What does the future hold for you and A?

Appendix 3C

Extract from Saskia's interview transcript showing early labelling of themes

Appendix 3C cont/d

Appendix 3C cont/d

Appendix 3D

Table of themes from early analysis to facilitate looking for connections

theme	page	turn	potential master theme
not expecting stroke - J healthy	1	2	J's stroke: stroke event
no experience of stroke / illness	7 13	90 182	no preparation for caring, no control
stroke moment (TIA)	1 2	2 6, 8	
S's recognition of stroke/symptoms	1 8	2, 4 112	stroke responsible for changes in J
stroke symptoms	1	2, 4	
family witness	1 2	2 10	
J's denial	1	2, 4	
family called	1	4	
family involved	1	4	
tests	1	4	
no information	1	4	
S's action	2 3	8 24, 28	
S's monitoring & reporting to docs	2	8	
feeling lucky	2	14	
hospital / therapists action	2 3 4 7	14 24 44-6 90	negative impact of profs' response
hard for S to deal with therapists' acceptance of J's minimal improvement and how they treat him: 'you're doing so well': <i>one of the hardest things... it makes me really angry</i>	16	238+	professionals re/actions different to S's own - they differ to S's anger
diagnosis & prognosis	2 7	16 90	
prognosis uncertain <i>won't live a long time</i>	10	146	
time in hospital	2	14	
S's responsibility for J	3 4	25, 28 40	S's drive to get J better
S's disagreement with docs/therapists - S knows best	3 7	26 92	hope
stimulating J	3 4 5	30-6 38 56	work ethic
<i>life was sweet</i>	8	102	S's drive to get J better
S 'works hard' on J	3 7	30 92	work ethic hope
S's focus on J's needs	3	30-2	S's drive to get J better
S as teacher	3	32	
child like activities	3 4	32-4 46	J a child
S's health suffers	4	38	impact of caring on S
tired	4	40	impact of caring on S

Appendix 3D cont/d

everyday life continued	4	40	
expectations of care-not good enough	4	42	S's drive to get J better
S as agent of J's recovery/motivator	4	42-6	J a child
control through activity	4 7 8	44 92 102	control hope
J hard worker pre-stroke - the provider & valued, now <i>feels useless</i>	9	118	comparison of J pre/post stroke J's self concept work
J's speech and language diffs	2 5 6 7 15 16 16 16 15	18 54 77-80 82+ 220+ 230+ 200 226+ 234 212	impact of stroke on J J's loss comparison of J pre/post stroke loss of communication for family loss of conversation
diffs finding family names (early post stroke)			
diffs understanding			
can't have a conversation with him <i>one of the things I miss</i> S has to control conversation -hard work J's comp probs <i>frustrating</i> for S, got worse over time			
S has to talk for him			
J's memory probs	15	212-6	impact of stroke on J
J's life altered - no hobbies, reading, work - <i>devastated</i>	5 6 7 8 10 9	54 68-70 88 106 132 118 212	impact of stroke on J J's loss comparison of J pre/post stroke comparison of J pre/post stroke - work ethic
pre stroke work came first			
J's daily activity now - class, TV	14		
J's personality altered	6 8 8-9 10	68-70 102 106- 16 140	comparison of J pre/post stroke J's personality J's loss comparison of J pre/post stroke comparison of J pre/post stroke J a child J a child
J's seizures - more brain damage	5	56-66 148-	J's medical probs
done less, knocked confidence <i>totally given up, regressed</i>	11	54	comparison of J post stroke/post epilepsy loss of hope
J's acceptance of life after stroke - won't work	7	93	J's acceptance
S's hard work on J wasted	5 11	56-64 154- 64	loss of hope

Appendix 3D cont/d

S protecting J	6	68	J a child
S's loss of husband / life	7	86	S's loss
	10	136-14-	comparison of S pre/post stroke
<i>life is so different - in limbo</i>	12	174	comparison of life pre/post stroke
no spontaneity	13	184	
loss of family activities - family also lost out	13	192-200	comparison of life pre/post stroke
Searching for man she's lost	10	138	
<i>I really want that man back</i>			
need to return to normal	7	94	need for normality
S not allowing J to admit defeat: <i>life is still good</i> (this not evident in previous text)	9	130	need for normality
reasons to be cheerful			reasons to be cheerful
J doesn't get depressed	10	136	
live in a beautiful place	23	178-80	
S's burden of greater responsibility	10	140-4	comparison of roles pre/post stroke - control
loss of partnership	10	142	loss
<i>I haven't got a husband</i> - relationship unequal, one-sided	14	202-212	loss, comparison with life before stroke, meaning of marriage
doesn't know what future holds <i>worst thing</i>	10	144-6	uncertainty
J's death: when?		151	loss (of control)
waiting for more seizures	11		
	10	146	uncertainty
glad he's alive V wishes he was dead	11	146	
progress = hope	12	164-6	loss of hope
happiness = life as it was	12	174-6	?drive to self actualisation?
		180-2	
being alive isn't enough	13		
S caring for J's ADL a burden	13	184	loss of relationship
<i>everything's a struggle</i>			
sons lost their dad - hard for them plus implications for J's self concept	13	194+	J's self-concept
			loss for family
J egocentric now - doesn't really think of S's needs	14	208	changed relationship
J's daily activities now	14	208	J's life post-stroke
class, TV, gets fed			
hopeful phases early post-stroke	16	224	hope

Appendix 3E

Headings of clusters of related content from early analysis of interview, and phases to which they correspond

Interview content	Phase/s to which content relates
Not expecting stroke	2
No experience of stroke	2
The stroke event	2
In hospital	2-3
Diagnosis and prognosis	2-3
Immediately post stroke	2-3
During time J in hospital	2-3
Bringing J home for first time	2-3
Dealing with professionals' responses over time	2-4
Need/hope/striving for normality	2-3
S takes responsibility for stimulating J: agent for J's recovery/motivation	2-3
S 'works hard' on and for J in short and long term	2-4
J's seizures: more brain damage and loss	4
J's severe physical impairments: S has to do most AsDL for him	2-4
J's severe speech and language difficulties	2-4
J's post-stroke memory problems	2-4
Stroke and resulting impairments = S's perception of loss of J's life as he knew it	3-4
Loss of partnership/relationship: S loses J the man, J the husband and gets J 'the child', J 'the imbecile'	3-5
S loses her own and their shared life as she knew it	3-5
S the teacher/therapist/mother: S treats J as a child/imbecile and J acts/reacts accordingly	3-4
Sons' responses	1-5
Friends reactions	2-5
S's burden of responsibility	3-5
Stress of caring for J has caused S's health to deteriorate	3-5

Appendix 3E cont/d

Loss of self: S changed as a person	4-5
J doesn't/can't try hard enough for S: she thinks he has given up	4-5
S meeting her own needs	3-5
Respite from caring: enables S to cope but feels guilty	4-5
Not coping: S the failure?	4-5
Acceptance	4-5
Uncertainty about the future: the worst thing	1-5
Death wish	4-5
Life after J's death: freedom and relief	5

Key to phases:

Phase 1: life pre-stroke

Phase 2: Jim's stroke

Phase 3: rescue mission and hope

Phase 4: endurance, loss and hopelessness

Phase 5: regeneration

Appendix 3F

Extract from table containing clusters of related content, developing analysis and supporting evidence

clusters of related content from early analysis (bold); evidence: summaries of text (plain), or <i>verbatim quotes (itals)</i> ; developing analysis/comments on evidence etc	page	turn	Analysis: Initial analysis (plain) developing analysis, questioning of it, comments etc (blue) THEMES FROM / IN THE ANALYSIS (BLACK OR BLUE CAPS)
not expecting stroke <i>perfectly fit & healthy... never been to the doctors in his life</i>	1	2	No preparation for stroke Low level of interest/significance
no experience of stroke if you've never had any experience of strokes, you don't know what to expect <i>... when you have never been ill and it's suddenly thrust upon you, you don't enjoy life the same</i> <i>no concept of what a stroke entailed at all</i> not sure I believe this: After all she says she knew he was having a stroke (1.2) – therefore thought <i>a couple of weeks, back to normal</i>	7 13 36-7	90 182 548-51	no preparation for stroke / caring: no control sudden nature of stroke that is difficult, ie rather than progressive illness which you gradually learn to live with? Perhaps here she meant no notion that it would be a long haul
The stroke event <i>... J came home on 25th May 99...I spoke to him and... sort of garbled language came out, and... I realised immediately he was having a stroke... his face had dropped and he was dribbling. Doctor & family summoned; J partially recovered: had had 2 TIAs: there's nothing wrong with me at all. Family drove him to hospital, where had 2 more TIAs then major stroke: we saw him having it</i> low interest? Not referred to again	1 2	2-4 6-10	S recognised J was having a stroke therefore did have some concept of what one was? S and sons witness TIAs & stroke The beginning of the end of Jim the man and beginning of JIM THE IMBECILE: dribbling?

Appendix 3F cont/d

In hospital tests, doctors searching for bed but giving no information about what going on: S took responsibility for keeping docs informed of J's deterioration: <i>I called the doctor back... I think he has had a much worse attack</i>	1	4	At hospital: S keeping docs informed rather than other way round: S taking control beginning of her RESCUE MISSION
	2	8	
	3	24, 28	
Stayed with J until settled: <i>luckily</i> daughter in law a nurse at the hospital. J on ward overnight, to stroke unit next morning, scan.	2	14	Feeling lucky?! Yes, because knowledge is power is control?
Started physio <i>within a day or so</i> , SLT shortage so <i>hit and miss</i> : no therapy at w'ends: <i>just a waste so I opted</i> to bring J home every w'end, against hosp recommendation	3	24	Inadequate therapy: weekends a waste of valuable stimulation time; S took control: arranged more therapy: drive to get J better
J in hospital for 4 months, where <i>he did get on extremely well... he was progressing</i> . Then moved to stroke rehab unit for outpatient SLT/physio 3 days a week: <i>that was good as well</i> . Plus S arranged SLT for him at home (for 2.5yrs):	4	44-6	J made progress in hospital and at outpatient rehab

Appendix 3F cont/d

<p>diagnosis & prognosis: scan showed blocked carotid artery, <i>quite a bit of damage</i></p>	2	16	Extent of brain damage
<p>day after stroke, told: <i>your life will change now, it's not finished but it will be different... J will never walk, work, or drive again, well this was appalling.</i> S didn't tell J this. When seeking knowledge of stroke from consultant 8 days post-stroke, told same thing: <i>absolutely dumbstruck...I couldn't even listen anymore...I devastated... that was the first really big shock, more of a shock than the stroke because we just thought 'oh he'll get better'.</i> S preferred to listen to other 'experts' – OT, physio who gave more positive prognosis: huge relief, and glad to prove consultant wrong when he improved</p>	7 40	90-2 596- 608	<p>S's early reactions: shock, denial</p> <p>Negative impact of professionals' negative early response: S needed positive reactions, hope, needed to hear he would get better – ie to hear news that would fit in with her need for hope, to return to normality i.e., needed professional responses that fitted in with her notion of the drama/narrative that was unfolding ie within context of her as rescuer</p>
<p>poor prognosis: told <i>if we got past the first six months he stands a chance of a few years, but he wouldn't live a long time.</i> Living with uncertainty difficult – will he/won't he be alive in the morning? Also see death wish section</p>	10	146	<p>Expecting J to die: uncertainty difficult UNCERTAINTY - Will he die? 'Please god, let him live and I'll rescue him' (see 39.576) Later... 'and do I want him to die? Would it be for the best?' Eventually his death becomes part of her story?</p>
<p>told he <i>wouldn't improve that much</i> but S's response: <i>they don't know everything, I know he'll improve</i></p>	17	244	<p>Disagrees with professionals' diagnosis: hope Also see 'coping with professionals' response over time' section</p>

Appendix 3F cont/d

immediately post-stroke: minimising effect – ‘a blip’: <i>never mind, a couple of weeks back to normal</i> ; hoping he’d make a full recovery; bed-side vigil	36	548-552	COPING?: denial, minimising impact prompted by shock? Or did she really know nothing about stroke, in which case it wasn’t denial, just innocence? He did make good progress? Stoic
early days: just carried on as normal – walking dogs mornings, hospital every day, bringing J home every w’end: <i>desperately trying to cling onto life so when J came back here everything would be just the same</i>	36 41	552 612	+ + activity desperate need to keep everything as normal KEEPING THINGS NORMAL?
it was a just stiff upper lip, get on with it... keep everything as normal as possible so that J wouldn’t feel he was a burden, or that he wasn’t going to get better, and that things were going to be, just as they were	42	624-34	Need for normality Hope – for recovery
during time J in hospital: S looked after J every day in hospital, took over nursing duties, bathing. Brought him home <i>weekend after weekend</i> (4 months) to prevent him getting institutionalised & ensure his stimulation: J saw hospital as ‘home’ & S didn’t want his eventual coming home to be a wrench	42 3	618-22 24-8	Start of S’s role as carer, but at this early stage carer = RESCUER Took over his care in hospital, took responsibility for bringing J home at w’ends S in CONTROL COPING = success as director of rehab? later, NOT COPING = failure